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ABSTRACT

A collection of papers on the Australian experience with early intervention for children with disabilities gives regional overviews, describes specific intervention programs, and discusses a variety of issues. Overviews are given of early intervention in Australia in general, New South Wales, Victoria, Queensland, South Australia, Western Australia, Tasmania, and the Northern Territory. Topics of program descriptions include: the Down Syndrome program at Macquarie University; early education and integration for children with intellectual disabilities; hearing and hearing loss; visually impaired children; a New South Wales cerebral palsy program; the Autistic Association of New South Wales; early language intervention; communication camps; a University of Western Australia program; a rural community's child/parent support initiative; a rural distance education approach; a home-based teaching program; a program for urban migrant families; services in New South Wales preschools; and a toy library. Early intervention issues addressed separately include the working relationship between parents and professionals; teaching parents to be direct instructors and child advocates; integration of quality care and education; manual communication for hearing-impaired and autistic children; early special education teacher training; alternative and controversial treatments of Down Syndrome; evaluating early intervention programs; and the efficacy of early intervention with Down Syndrome. (MSE)

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EARLY INTERVENTION
FOR CHILDREN WITH DISABILITIES
The Australian Experience

Editors

Moira Pieterse • Sandra Bochner • Sue Bettison

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EARLY INTERVENTION FOR CHILDREN WITH DISABILITIES:
The Australian Experience

Moira Pieterse ☆ Sandra Bochner ☆ Sue Bettison

Special Education Centre
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This is a joint publication of the Research Committee of the Australian Society for the Study of Intellectual Disability (A. S. S. I. D.) and Macquarie University Special Education Centre. The editors wish to thank the National Council of A. S. S. I. D. for providing the stimulus for this volume by establishing the Research Committee and supporting the initial concept.

PREFACE

It cannot be denied that the editing of this volume has been a labour, but it has become a labour of love, as the richness of the contributions that were made by people working in all parts of Australia became evident. This is a unique collection; perhaps the first in what could become a series that will mark the growth of this so recently developed area of service provision in Australia. The Schonell Report (Watts et al, 1981) on early intervention in Australia (1979-80) located only limited numbers of programs in most of the States. For example, in New South Wales 'children under five with disabilities other than hearing impairments had no official government service provided for continuous developmental intervention' (Watts et al, 1981, p 30). Developments since that time have been remarkable, as evidenced by the reports included in this volume.

The extent of changes in this field are reflected in moves to set up early intervention associations in the various States. In New South Wales, the first meeting of interested groups was held in December 1981 and by 1984, when a survey of members was undertaken, it was found that 39 submission-based services were represented among the membership of the Association. By 1988, the N.S.W. Association had 160 members representing 140 services. In November, 1985, a public meeting was called in Melbourne and from that emerged the Australian Early Intervention Association, Victorian Chapter, which by 1988 had almost 100 individual members. An early Intervention Association for children with hearing impairments already existed and these groups, together, provided the basis for a strong pressure group to support the rapid changes that subsequently took place in that state. Many of the goals initially set when the Victorian Chapter was established have now been met and new objectives are being identified. Associations with similar functions exist in some other States; for example, South Australia and Tasmania, where an early childhood education group monitors developments in early intervention. There is strong interest in the establishment of similar groups in the remaining states. Such groups have an important function, both as a focus for support and development for staff who are often very isolated, professionally, and as a potential basis to lobby governments about needed changes to services. The support of such groups will be needed if changes in areas such as teacher training and employment conditions are to be achieved. Perhaps this volume will contribute to increased awareness, across all the States, for the need to establish structures whereby professionals and parents who are involved in this particular area of service delivery can work together to achieve shared objectives.

One of the difficulties inherent in the production of a volume of this type relates to the delay that can occur between the initial request for papers and the final publication of the book. The first call for papers for this collection was made in May 1985, and the final editing and type-setting was finished in May 1988. The time lag here seems excessive, but the task of actually assembling such a large number of papers and transforming them into a coherent collection for typesetting is an awesome task. This has proved to be a period of very rapid change in the field of early intervention, for Australians, so it is inevitable that this collection, in one sense, is almost an historical document by the time of publication, when the original aim was to provide a review of current developments. The inevitable discrepancy that must, therefore, result from inconsistencies between what is reported here and what is actually happening, at the time of publication, should be kept in mind when reading these chapters. There are some gaps in the topics that are covered here. For example, one of the early submission-based services in the Sydney area, which is not included here, was designed to provide support to teachers in preschools that were integrating children with disabilities or developmental delays. This model was later replicated in other programs around Sydney and undoubtedly, the fact that this service was already in place, facilitated the subsequent acceleration of the process of integration of preschool-aged children with special needs into regular preschools. This process was also facilitated by provision of the special sessional subsidy for integrated special-needs preschoolers. Similarly, there is no specific report on any of the professional development activities that have been undertaken in some States, often on the initiative of local branches of an early intervention association. This is an important aspect of the activity that is being undertaken by professional associations and it is particularly important in a rapidly developing field, where few formal programs for professional training have as yet been established, and where networking among professions in the field has not fully developed. These and other neglected areas of activity may be addressed in a subsequent collection of papers on this topic.

Finally, we would like to thank all those who contributed to the production of this volume, particularly the authors of the various chapters. Australia is a large continent and it is often difficult to know what is happening in a particular field in other parts of the country. The editing of this volume gave us an opportunity to make contact with colleagues in other States and it was good to have this chance to put a voice or, in some cases, a face to a familiar name. Some editorial changes were made to some chapters, to provide consistency across the various contributions. The editors apologise for any concern that this may have caused.

Over the period that this book was in preparation, changes have occurred in the terminology used in Special Education. For example, the phrase 'children with disabilities' is now used in place of 'the disabled child'. Similarly, 'Down Syndrome' is now used in preference to 'Down's Syndrome'. Both forms appear in this volume.

The editors
May 1988

Watts et al (1981) *Early Intervention programs for young handicapped children in Australia 1979-1980.* Fred and Eleanor Schonell Educational Research Centre, University of Queensland, St. Lucia.

PART 1

OVERVIEW OF EARLY INTERVENTION

Chapter 1

OVERVIEW OF EARLY INTERVENTION SERVICES IN AUSTRALIA 1986

S. Bettison

It is more than five years since the national review of early intervention in Australia (Watts et al, 1982). In that time major changes have occurred in all States, although many of the issues highlighted by the review have still not been addressed. During the period covered by the review (1979-1980), early intervention was in its early days. It is now one of the accepted range of services offered to people with developmental disabilities, and is one of the service types which have developed as part of the continuing trend away from nursing care, medical treatment and therapy as the dominant approach, towards a multi-disciplinary, developmental and educational focus.

The following group of chapters examines how early intervention has developed in each State, and discusses the nature of programs, factors influencing current directions, and problems to be overcome. The authors give their views of this development as seen from their own close involvement in early intervention over a number of years. Taken together, these chapters indicate some major influences, outside the programs themselves, which are shaping the kind of help received by individual young Australians with special needs, as well as, indeed, determining whether they receive any intervention at all.

Both Federal and State Governments have increased their involvement in early intervention since 1980, through increased funding and policy guidelines. In general, these policies have resulted in a proliferation of small, self-contained projects and a preponderance of centre-, rather than home-based programs, focusing on particular categories of disability. In more recent years, however, policies have begun to shift, reflecting changes in emphasis in the disability field, and are now moving towards more parent involvement, integration, normalisation, and an increasing focus on education as the major program component.

The number of early intervention programs has also increased substantially in most States since 1980. This growth has occurred in the continuing absence of any register of services or data on the unmet needs of young children. Victoria is the first State to attempt a full survey, through its current Early Special Education Needs Project. In addition, the Commonwealth Schools Commission's Advisory Group on Early Special Education (Andrews, 1985) made some educated estimates of need in Australia, and several studies (Nathan & Sultmann, 1981; Burge, 1984) have provided partial prevalence data for Queensland. However until such information is generally available, early intervention will continue its ad hoc evolution, leaving inequities and gaps in every State.

The fragmented and complex pattern of funding and responsibility for early intervention services, reported by the national review in 1982, continues to create problems in most States.

Tasmania and Queensland are the only States to have progressed towards a solution to these problems. This is being achieved through the gradual assumption of responsibility for early intervention by the Departments of Education in the two States. Western Australia has generally experienced less fragmentation in early intervention because of the major role of the Mental Deficiency Division of the Department of Health (now coming under the Authority for Intellectually Handicapped Persons). In all other States, a number of Federal and State Departments and some local governments administer the funding of early intervention programs which are provided by a proliferation of government and voluntary organisations. The problems this causes have intensified since they were noted by the national review. There are now many more projects competing for funds, and many programs live a hand to mouth existence, relying on several funding sources, all of which have different policies with few guarantees of continuing support. In the following chapters, several authors report additional difficulties arising from recent changes in both Commonwealth and State Government funding responsibilities. Victoria and South Australia have both experienced major transfers of early childhood and disability services between Departments, with the inevitable restructuring and policy changes which such transfers involve.

Perhaps the major issue raised by the following chapters is one of program quality and benefit for the young children who participate. Early intervention is not a unitary concept, as the national review demonstrated. It has become a catch-all term often used to encompass almost every type of regular, non-medical contact with a child under school age which purports to influence the child's development. Programs range from group play once or twice a week in a preschool setting to highly structured and intensive individual teaching directed at specific goals for each child. Most programs aim to enhance development by counteracting developmental delay or impairment. However, there has been no examination of whether these, or any other outcomes, have in fact resulted from early intervention. This means that funds are being allocated and many policies and programs developed in a vacuum, with no certainty that young Australian children in need are actually benefitting.

Most authors indicate that many children are still not involved in any program until three or four years of age. When children do enter intervention services, the financial resources and expertise are often not available to provide structured programs with built-in monitoring of each child's progress towards planned goals. Western Australia and Queensland are two States which are moving towards a Statewide comprehensive early intervention system, with guidelines for program design and management. Western Australia, however, is still the only State which has attempted to build a system of ongoing evaluation into its programs.

The continuing need for staff training and support was noted in nearly all States, as was the difficulty of ensuring that early intervention teams include the full range of skills required. Sometimes this difficulty is a direct result of Government policy which does not allow, for example, Education Departments to fund personnel from traditional health or welfare disciplines. In other instances, qualified health and welfare professionals are not entering the early intervention field because their training has not given them the relevant skills and orientation, or the programs seeking their services cannot offer secure employment.

Many of the issues highlighted by this section are indicative of a vigorous and fast-growing area of service which has received strong commitment from Governments across Australia. The co-ordination required to improve equity and service quality is just beginning to emerge in most States. There are also indications, at least in some States, that the current diversity and fragmentation is being replaced by more formal systems. Whether this is for the ultimate benefit of young children with special needs, and whether it occurs at all, will be greatly influenced by the political and economic climate in Australia over the next few years.

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Chapter 2

EARLY INTERVENTION IN NEW SOUTH WALES

a mosaic of policy and practice

Joy Goodfellow

Interest in and concern for the provision of early intervention services in New South Wales became evident during the 1970's. The Macquarie University Down Syndrome Program (Pieterse, Wade, Morrison, Thompson & Uther, 1985) was begun in 1974 to investigate the efficacy of early intervention with intellectually handicapped children aged 0-6 years and to develop teaching techniques and curriculum. The Early Education Clinic, a replication of the Macquarie model, was established at Cremorne in 1979 following the positive response of the Department of Youth & Community Services to requests for funding. This program subsequently moved to other facilities at North Sydney and Parramatta. Programs for preschool early intervention and baby stimulation were commenced at Newcastle College of Advanced Education and Mitchell College of Advanced Education, Bathurst, also established an early intervention program. These university and college projects demonstrated the value of early intervention and stimulated demand for services by parent and community groups.

During this period there was also a growing awareness within the community of the value of integration and an increasing understanding of the rights of disabled people to have access to, and be included in, generic services whenever possible (Goodfellow, 1980). The introduction in 1980 by the Department of Youth and Community Services (YACS) of subsidy funding for children with special needs in community-based preschools drew attention to the need to provide developmentally appropriate individualised programs for these children in generic services. At this time also, the first Education Support Service was funded by YACS to assist teachers to develop and implement individualised programs for children being integrated into community-based preschool centres (Shields, 1981).

This paper highlights some of the factors which have contributed to the development of early intervention in New South Wales. It outlines funding sources, identifies initiatives undertaken by State departments and voluntary agencies and pinpoints areas of concern to all those involved in the provision of early intervention services.

Early Intervention Programs

Initially, establishment of early intervention services (outside those of the tertiary institutions) tended to be the result of parent or community initiatives to provide for the needs of specific groups. Older programs therefore reflect a segregated rather than integrated approach; for example, the Spastic Centre has Early Treatment Clinics which provide services for children with cerebral palsy and/or those who have neurological signs associated with developmental delay; the Royal N.S.W. Institute for Deaf and Blind provides assessment, home-based therapy and itinerant teachers who visit preschools to assist staff in the implementation of programs for children with hearing and visual impairments. Subsequently, most programs were established to provide services for children with a broad spectrum of disabling conditions; for example, a home-based service introduced by the Challenge Foundation in 1980 provides early intervention for infants and young children with developmental delay. This project, which followed a transdisciplinary model involving a physiotherapist, occupational therapist, speech therapist and special educator (Jolley, 1981) was initially funded through the Commonwealth Government's Office of Child Care. In the southern metropolitan area, Bexley Therapy Centre, which was largely funded by the N.S.W. Department of Health, provided assessment and early intervention for children 0-5 years who were developmentally delayed.

Early intervention/education services funded by a variety of sources, including both Commonwealth and State government departments of Health, Welfare and Education, now operate in each region of the State. They have been established as a result of individual submissions and so can vary considerably in mode of operation. Most are community managed and employ staff which 'best fit' the needs of the service which may provide some or all of the following components:

- early identification
- developmental assessment
- individualised programs
- parent education
- information/advice/referral
- preschool follow up
- centre/home visits
- co-ordination with other services
- parent/family support
- toy library

A number of additional services for young children are currently available, including developmental playgroups, itinerant education support services and programs for more severely handicapped children. For example:

1. **Developmental Playgroups** have largely been established by the Challenge Foundation and are funded by YACS. They operate throughout the metropolitan area and in the Western and Hunter regions and provide, in addition to skill development, an opportunity for interaction between the disabled child and peers as well as between parents sharing similar concerns.

2. **Itinerant education support services** are designed to assist and support staff in community child care centres, to assess, develop and implement individualised programs for the 'special needs' children being integrated into those centres. A small number of such services operate in the metropolitan region and YACS also funds an itinerant service at Griffith in the Riverina and at Goulburn in the Illawarra Region.

3. **Intervention services for the more severely handicapped children** have generally lagged behind those for other children. A number of these children are in institutions with the Department of Health having responsibility for care of the majority (Ferguson & Ward, 1984). The Department of Education has not, in the past, taken responsibility for these children until they reached four years of age. However, it is involved in the Liverpool Early Education Project home and centre-based service which began in 1983 with funding from the Commonwealth Schools Commission through the Severely Handicapped Children's Program (Lewis & Ferguson, 1985).

A survey of services by the N.S.W. Early Intervention Association (1984), identifies a number of interesting features in relation to type of service, staffing and funding source which are characteristic of programs in New South Wales (copies of relevant tables are available from the author on request). For example, there are inconsistencies between regions both in the **number** and **type** of services provided. For example, in relation to the number of services available, provision in the Riverina and Western regions is sparse when compared with the number of services within the North Coast or Sydney metropolitan area. There are few services in the State which are solely home-based, though many centre-based services provide home visiting as well. The **staffing** pattern varies considerably between services. Special educators are employed in 77% of the programs identified, speech pathologists in 28%, physiotherapists in 29% and occupational therapists in 28%. The special educators have differing qualifications and include some who have undertaken graduate diploma courses in special education or are teachers who have trained in fields other than early childhood or special education. A number of initiatives have been taken to ensure that appropriately trained special education staff are available. For example, in 1985, the Kindergarten Union of New South Wales ran short inservice courses to equip 121 assistants to work as support staff for children who were being integrated into their centres.

As far as **funding** is concerned, 79% of the services receive YACS funding which is in keeping with that department's responsibility for provision of childcare services. However, the unequal distribution of services across regions highlights one of the problems associated with submission-based funding, where it is difficult to get a pool of people together in some regions in order to present a submission and administer the service.

Constraints on the development of services

Whilst many young disabled children of preschool age have been accepted into generic services in this State for quite some time, the lack of funding and expertise, insufficient childcare places for all children of below school age and problems associated with population distribution have all contributed to the difficulty of establishing a network of appropriate early intervention services.

New South Wales covers an area of approximately 801,400 square kilometers and has a population of 5.5 million (the largest of any State). Of the 485,000 children in the 0-5 age range in Australia, just over one third live in New South Wales and, if one takes a conservative prevalence figure of 3% (Andrews, Elkins, Berry & Burge 1980; Commonwealth Schools Commission, 1985b), then there are an estimated 14,550 children in need of early special education services in this state. Providing generic and specialised early childhood services for this group of children is fraught with problems, not the least of which is the provision of equality of access in areas of low population density. About 63% of the people live within or in close proximity to the Sydney metropolitan area (Australian Bureau of Statistics, 1984;1985), while the western half of the State is sparsely populated, with many families living in areas which are subjected to hot, dry climatic conditions and where difficult terrain and poor communication facilities contribute to their isolation.

Another issue attracting considerable debate in this State is the co-ordination of services. A review of early intervention programs in Australia (Watts et al, 1981) found that, whilst the various government departments had wide powers enabling them to provide services for young children with disabilities, none had specific responsibility in this area. As a result, there seemed to be some confusion as to the particular role which government departments and agencies should play in providing early intervention services. Whilst voluntary associations and private organisations do provide some early intervention services, it is largely the responsibility of governments to provide health, educational and welfare services which are equitable to all.

To date, the specific responsibilities of the departments have not been clearly identified; each has a view on early intervention and has taken steps over recent years to provide appropriate services within its existing areas of responsibility. This has resulted in a significant contribution to the development and funding of services being made by YACS, since it has been largely responsible for children's services, with the Department of Health responsible for diagnosis and therapy. The regional boundaries for these services within the Departments of Health, Education and YACS are almost identical, though only the greater Sydney metropolitan area has common boundaries to all departments. However, within that area, YACS and Education have four regions and the Department of Health only three. Whilst this is cumbersome and may appear confusing to recipients of services, there is much more collaboration between departments at the local level than first appears, as well as some sharing of responsibilities for people with different categories of disability.

In the past, YACS had an arrangement with the Department of Health whereby it took responsibility for persons who were mildly and moderately intellectually disabled while the Department of Health cared for those with severe and profound disabilities—'the 1964 agreement', (N.S.W. Department of Youth & Community Services, 1985). Recent discussions have considered whether it might be more appropriate for this department to move towards providing more parent support services, such as respite care, rather than supporting early intervention programs which have an educational component. One of the issues here is that the department is responsible for generic early childhood services and it adopts the principle of normalisation as a philosophy; so the facilitation of integration of young developmentally delayed and disabled children into generic services must also be addressed.

The following overview of policies and practices of government and non-government agencies which have supported the development of early intervention services, the rationale for their development and factors which restrict the availability of appropriate services for all who require them provides a basis for the identification of some of the current issues of concern to those associated with early intervention.

Department of Youth & Community Services

Among the various Government departments, YACS has been responsive to requests by parents and other interested persons for the funding and development of early intervention services. It must be remembered that this Department is responsible for generic children's services (to which all children have access) in accordance with the regulations accompanying the Child Welfare Act (1939) and more recently, the Community Welfare Bill (1982). This responsibility includes the licensing of child care centres, and the provision of pre-school subsidies (including the current special subsidy of $8.50 per session for each disabled child being integrated into a community based pre-school). The Pre-school Subsidy Manual (N.S.W. Department of Youth & Community Services, 1983) and Handbook for Childcare Centres (Department of Community Services, 1986) both state that disabled children have priority of access to children's services, (this reflects the Commonwealth's conditions for block-grant funding).

The major direct service provided by YACS to young disabled children, their families and the community at large is the Young Disabled Children's Program. The Program has 14 co-ordinators whose responsibility it is to develop and/or extend local community resources to meet the needs of young disabled infants and pre-school aged children and their families. The co-ordinators have been responsible for initiating and/or contributing substantially to the establishment and development of a number of community organisations which provide specialist services such as early intervention, respite care and developmental playgroups. These services are funded through the 'Assistance to the Disabled' sector of the Department's Community Welfare Fund.

Department of Health

Instrumental in the recent development of the Department of Health's policy on early intervention has been the Inquiry into Health Services for the Psychiatrically Ill and Developmentally Disabled, (Richmond, 1983). The Department adopts the principles of normalisation as its philosophy and recommendations from the Richmond Report have been incorporated into Departmental policy which acknowledges its responsibility to the disabled (particularly those with severe or profound intellectual disability), including the provision of appropriate diagnostic, assessment and therapy services (N.S.W. Department of Health,-1985) for children at a very young age. In the past, difficulty has been experienced by the Department of Health in employing educators, as Department guidelines have not included personnel other than health professionals and support staff. Intervention therefore has had a therapy/medical orientation where treatment of specific problems was undertaken by therapists who were seen as the appropriate professionals for providing intervention with younger children, particularly the 0-3 year olds.

The Richmond Report also recommended that a range of early intervention programs be developed in consultation with the Department of Education and the Department of Youth and Community Services. Specifically, the policy document on developmental disability services (N.S.W. Department of Health, 1985) states that each of the eleven health regions in the State should establish a three-phase post-natal screening program and referral to the Area Developmental Disability Teams within each health region. The Department of Health therefore has responsibility for diagnosis and psychological assessment of young children with developmental disabilities. Such children, particularly those whose problems are less severe, are now being seen at a much younger age and this provides the opportunity for intervention, particularly where referral can be made to appropriate services which exist in the community. A good example of interdepartment co-operation is the situation in the Northern Metropolitan Region where the Education Support Service, which is funded by the Department of Youth & Community Services (Shields, 1981), receives referrals following assessment by the multidisciplinary team at the Chatswood Assessment Centre and provides educational intervention in community-based children's services in consultation with the child's parents and therapists as required.

Department of Education

In this State, the Department of Education has played a very limited role in early intervention services for young developmentally delayed children. The compulsory age for school entry is 6 years; however, most children enter school at 5 years of age. It has provided an itinerant educational advisory service for deaf and visually impaired children of below school age from time of diagnosis and makes provision for enrolment into special classes from age 3. Only in recent years have initiatives been undertaken to provide educational services for children of below school age who are developmentally delayed. Children with moderate or severe/profound intellectual disability may be enrolled in Schools for Specific Purposes at 4 years of age. In special cases, 3 year olds may be enrolled when referred by the Department of Health and approved by the Regional Director of Education.

A report (Doherty, 1982) commissioned by the Minister of Education acknowledges the crucial importance of early intervention in fostering the cognitive-intellectual and social-emotional development of children and in providing support for their families. The Report made a number of recommendations to the New South Wales Government for the development of a range of home-based, centre-based and itinerant early intervention services which provided for the development and implementation of individualised programs for children from the age of identification. A major concern in the Report was the need for consultation between Ministers of Health and YACS to develop better co-ordination of services for children 0-5 years. It was therefore suggested that a central committee of specialist advisers from each department along with a network of local co-ordinating bodies be established. The co-ordination of services was also seen as a means of facilitating a multi-disciplinary approach to diagnosis, assessment, referral procedures and service delivery. This report was rejected by the subsequent Minister for Education. However, it still remains the only public source of policy.

As an indication of its interest in and concern for early intervention, the Department of Education in 1985 operated two pilot projects for early childhood special education, in the Metropolitan West area (State funded) and at Liverpool, in conjunction with Challenge Foundation of New South Wales (Commonwealth funded) for young severely handicapped children. Another significant step undertaken by the Department of Education was to provide for the training of a small number of early childhood special educators. At the beginning of 1986, 14 early childhood special educators were appointed. Their roles were to provide centre-based services for young disabled children who were over 3 years of age.

Voluntary and Nongovernment Organisations

There are a number of associations and nongovernment organisations providing services for young developmentally disabled children and their families, such as the Spastic Centre of N.S.W., Challenge Foundation of N.S.W., the Association for Children with Learning Disabilities and The Autistic Association of New South Wales (N.S.W. Early Intervention Association, 1985b). Many of these organisations were developed as a result of parent initiatives and have subsequently received funding as a result of submissions to Y.A.C.S. as well as the Commonwealth Government. Most provide services directed towards specific target groups. For example, the Shepherd Centre for young hearing impaired children was established as a result of parent initiative which involved a considerable amount of voluntary work including fund raising. It now receives some funding from YACS and provides a home and centre-based program. The Kindergarten Union of N.S.W. which is the largest organisation to provide childcare services, supports the integration of those children who are developmentally disabled or 'at risk' of delayed development if it is considered that they will benefit from the program. In 1985, 74 centres had enrolled children who received the 'special needs subsidy' (paid by YACS). This represented 5.6% of the total number of children enrolled (Kindergarten Union of N.S.W., 1985; Langley, 1986). An early childhood special education adviser oversees the integration of the children who have special needs into the child care centres and the development of individualised programs. In many instances the special needs subsidy is used to employ support personnel who assist in the daily implementation of these programs.

Along with an increasing involvement in the provision of generic child care services, there is an emerging interest by local governments in the development of support services for young children who are developmentally delayed or disabled, and their families. In the Sydney Metropolitan area a small number of councils (e.g. Marrickville) have employed early childhood special educators to assist in the integration of children into regular community child care services.

Overall, it is evident that both Federal and State Governments generally support early intervention, initially, through party platform statements referring to 'the . . . provision of services for minority groups in terms of language, culture and special needs' (Australian Labor Party, 1984, p.204) and subsequently, through policy and funding. At the national level, the Commonwealth Schools Commission, in order to facilitate the establishment of early special education services, currently provides $727,000 (i.e. 19% of total allocation to all states and territories) to N.S.W. through the Early Special Education Program (Commonwealth Schools Commission, 1985a) to support the initiatives of government agencies and community groups in providing funds for early intervention, integration into regular pre-schools, toy libraries, research, curriculum development and minor modifications to buildings.

However, the Federal Government has recently been made aware of a number of concerns regarding early intervention services. The Advisory Group, appointed by the Schools Commission in 1984 to report on future policy, operations and directions for the new Early Special Education Program, noted the complex pattern of service provision in the states, and the uneven spread of services across geographical regions. It expressed concern for the need to have a better co-ordination of services (Commonwealth Schools Commission, 1985b) and identified the short-term priorities for development as being the provision of more combined centre and home-based services, itinerant services where parents are the major participants, and the integration of disabled children into generic children's services. Research and development, professional training and training for parents were considered as longer term goals. The Handicapped Programs Review (Grimes, 1985) has called on the Commonwealth Minister for Education to consider the further development of home and centre-based early intervention programs and a significant rationalisation of the roles of Commonwealth, State and non-government organisations.

In reflecting Federal Government policy of normalisation through integration of the developmentally delayed or disabled into generic government and non-government services (wherever possible), the N.S.W. Labour Party Platform indicated that special education services should be provided 'as soon as an educational problem is identified . . . (and that) . . . additional trained staff should be provided for the effective pre-school intervention for all handicapped' (A.L.P. 1984, p.13) and mechanisms should be established for the early detection of handicapped children before they enter school. The N.S.W. Anti-Discrimination Board report, Discrimination and Intellectual Handicap (1981) strongly recommended that the N.S.W. Government develop and implement a comprehensive policy on education services for children with 'intellectual handicap or developmental delay' and that this policy address

- children in all geographical areas of the State;
- all aspects of service delivery for assessment through intervention;
- the need to provide a variety of service types incorporating playgroups and parent education programs;
- the need to vary the approach from home to centre-based—segregated to integrated;
- the quality of programs presented.

In addition, it was recommended that a central planning and co-ordinating body be established within the Premier's Department to oversee the allocation of funds and the development and delivery of services in New South Wales.

Two advisory mechanisms for the planning, implementation and monitoring of services have now been established by the N.S.W. Government. These are **The Disability Council of N.S.W.** which reports to the Minister of Youth and Community Services, and the **Disability Services Co-ordination Unit** within the Premier's Department which is responsible for advising the Premier as well as co-ordinating the functions and services of all relevant Departments.

One of the priorities of the Disability Services Co-ordination Unit is to investigate the provision of early intervention services and give consideration to a means by which better co-ordination of services can be achieved.

CURRENT ISSUES

1. Staff

Current literature (Bricker, 1986) identifies that effective programs should begin as soon as the child is identified, have a purpose (identified by goals and objectives), provide structure, be monitored in their implementation and have significant parent involvement. One of the difficulties experienced by staff in generic children's services is that, while in the past they had little training in special education, they were often largely responsible not only for identifying a child as requiring special education services, but, in many other instances, also responsible for providing such intervention services themselves. Currently, staff are still expected to undertake positive intervention. Application forms to YACS for subsidy for a handicapped child and Commonwealth Schools Commission submission guidelines require that each child's area of disability be identified, wherever possible, since, by focussing attention on areas of major concern it is envisaged that the beginnings of individualised intervention can occur, as soon as a child's special needs are recognised.

Staff in generic services which integrate developmentally delayed and disabled children also accept considerable responsibility for these children and recognise the need for both professional support and the opportunity to undertake further training. They must work in close liaison with other professionals and develop a sensitivity to parents needs. In addition, the fact that intervention services are geographically scattered means that many staff feel isolated and lack opportunities for mutual support. The formation in 1983 of the Early Intervention Association has provided a vehicle for communication between professionals working in early intervention as well as offering opportunity for professional development through seminars and conferences.

2. Parents

Parents have a major role to play in the determination and successful implementation of intervention strategies which can result in significant benefits to the child. They are the major provider of service to their young disabled child and the extent to which they see their needs and those of their child being met by services is of paramount importance. Rees and Emerson (1984) undertook a survey of 51 families in the western metropolitan area of Sydney who cared for a young disabled child and found that the parents' major area of concern was the lack of co-ordination of services both within and across departments; not only was there the problem of insufficient resources but in some instances there were comments about **over** servicing. Parents felt that, in some instances, services were competing for clients and resources, rather than being complementary to each other. Concern was also expressed about the lack of freely available information; as one mother said — 'you need to know what services are available and then how to use the system'.

It is difficult to provide families with acceptable and continuous forms of support in a system where the responsibility for services provision is not clearly delineated and where the service provider for children of 0-3 years may be different from that provided for both the preschool (3-5 year)s and the school-age child. The possibility of ongoing program development for the disabled child is limited, as is the opportunity for parents to experience continuity of service.

3. Families in isolated rural areas

Whilst distance can be a problem for parents, it is also a problem for service providers where children requiring service are scattered over vast areas. The paucity of service provision and the vast distances to be covered in the western and south western regions of the State were noted earlier. In a survey undertaken in 1985 of families living in isolated areas of Australia who had a disabled child, the Uniting Church attempted to identify the number of children requiring service and the extent to which their needs, and those of their families, were being met (Uniting Church National Mission, Frontier Services, 1985). This project, supported by a grant made under the Projects of National Significance Program of the Commonwealth Schools Commission, identified 250 children under 4 years of age in N.S.W. who required additional specialised services and were living in areas recognised by the Commonwealth Taxation Department as burdened with additional financial costs because of isolation. (This area occupies the western and north western half of the State and covers about 400,000 sq. km.) Often parents travelled **across** regions for a particular service. In a report of the northwest area of the State, Edwards and Shaddock (1984) found that 91% of parents of severely handicapped children used clinics outside the region. Such travel means additional expense, which is borne either by parents who travel to services or by any service which operates on an itinerant basis. From evidence available it would seem that most developmentally disabled children in New South Wales who have been identified do receive some service; however it is often intermittent and frequently there is no provision for systematic educational programming.

Innovative ideas about ways in which the needs of isolated families can be met have been proposed. The use of teleconference for five isolated children of pre-school age in the New England area (Shaddock & Edwards, this volume) demonstrates a means by which specialised support can be provided. Other means of communication which have been used are video as well as photographs and written descriptions of strategies to be used with a child. Recently, the Commonwealth Schools Commission funded the Macquarie Down Syndrome Program to present its curriculum materials in video and accompanying resource book format so making them available for distribution to teachers and parents in isolated areas (Pieterse et al, 1985).

The concept of disability is one with which aboriginal people struggle; however disability and isolation can apply to this group of people as much as it does to any other. In addition, it is important to understand the relevance of disability within the context of aboriginal community life. Some aboriginal children attend the Bourke Early Intervention Program, where a family member is requested to participate in the program with the child. In the Hunter region of the State, the Taree Early Education Service has employed an aboriginal aide to assist families involved in the program.

For the migrant family with a disabled child, social isolation compounded by the lack of English presents additional problems to those experienced by most parents. Knowing about services that exist and what they have to offer poses an even greater problem for these parents than it does for other families. Confusion about the functions of various services (e.g. multi-disciplinary health teams, assessment centres, baby health centres, early intervention programs) may result in a delay in using services or not using them at all (see Croll, this volume). A number of cultural groups in Sydney have taken positive steps towards obtaining services. The Yugoslav Australian Association, for example, has received funding from the Schools Commission towards the cost of an itinerant early intervention program with a small group of children.

4. Funding

Level and continuity of funding is a major concern to many services for it reflects on the quality of staff a service is able to employ, the extent and frequency of operation and the nature of service provision to children and families (N.S.W. Early Intervention, Association, 1985a). Many services operating with scant resources attempt to provide some kind of service to as many children as possible to the detriment of quality. There is currently no mechanism for monitoring the provision of quality services and certainly no funding to undertake evaluation.

5. Management issues

Approximately 87% of early intervention services in New South Wales are managed by community committees which receive the funds and administer the service (N.S.W. Early Intervention Survey, 1985a). Submission-based funding also supports the responsibility of community groups to engage staff and oversee service delivery. This can present problems for teachers where the management committee is not conversant with the role and responsibilities of teachers, and award conditions. It is assumed that, within its members, the committee has the expertise to also undertake accounting tasks, write submissions for funding, promote the service and in many instances, act as an advisory body. Usually the level of funding does not permit the employment of personnel with the necessary skills, therefore the committee must be able to attract people in the community who have the expertise to undertake the various tasks involved. There is a need to provide clearer guidelines for management committees to enable them to carry out their roles more effectively.

6. Responsibility for service delivery

The use of generic children's services to provide for the needs of young developmentally delayed and disabled children is congruent with the principles of normalisation and the successful integration of these children into regular pre-schools in New South Wales is evidence of the value of this system. However, as noted earlier, there is need for YACS, who have been supportive of early intervention from the start and who fund community and voluntary groups to deliver services, to provide for the supervision and quality control of these services. There is also the need to have a mechanism for interagency and interdisciplinary co-ordination within the field of early intervention service delivery.

FUTURE DIRECTIONS

The major issues which have been addressed relating to the delivery of early intervention services are largely funding and delivery of services, staffing, curriculum development, research and evaluation. These are issues which have been identified by parents and staff involved in early intervention services and are recognised by the funding bodies.

Concerns in the area of **funding and delivery of services** highlight the need for adequate funding of services, for funding bodies to provide clearer guidelines and more direct support for the development of services (particularly where they are community managed) and for services to demonstrate accountability through appropriate evaluation procedures. More adequate resource information should be made available to parents through local community centres such as Baby Health Centres, so that they can receive some assistance in gaining appropriate services for their disabled child.

Secondly, as far as **staffing** is concerned, attention must be given to the provision of courses which most adequately equip staff to act in their roles whether they are developmental/educational specialists, early childhood special educators or acting as assistants or aides facilitating the integration of children with disabilities into regular services. Co-operation between professionals from differing disciplines needs to be continually fostered. The issue of support for staff could be met if consultancy/resource personnel in early childhood special education were to be provided in each major regional area in the State. These people could also assist with the dissemination of resource information to those working in isolated areas.

The third area of major concern is that of **curriculum development and research**. There is a need to address the question of appropriateness of services for disadvantaged groups (eg. aboriginal and isolated families) and consider the extent to which they take into account the social and cultural experiences of the parents. Further development of screening and assessment devices and other curriculum material appropriate for the various populations should be undertaken. Consideration must also be given to extending intervention strategies downward to meet the needs of 'at risk' babies in neonatal care units.

Lastly, with concerns being expressed about the need for both process and outcome evaluation to occur, it seems that funding bodies could make more positive steps to support evaluation, to guide the development of individual programs for children, provide feedback about the success of individual programs and to provide a means by which the quality and other aspects of the service can be monitored.

CONCLUSION

The growth of early intervention services in this State has largely come about through initiatives funded by the Department of Youth and Community Services. This Department, which is responsible for generic services for 0 – 5-year-olds, has facilitated the extensive integration of developmentally delayed and disabled children into regular childcare services in New South Wales. This co-ordination and integration of services is in accord with this Department's role. A number of recent initiatives have, however, provided impetus for change in the provision of early intervention services in New South Wales.

Initiatives, reports and recommendations regarding all aspects of funding, management and service delivery have come from a variety of sources, during the past five years. The Anti-discrimination Board and the Departments of Health and Education have each addressed services for the disabled and acknowledged the value of early intervention. Professionals and parents have seen the need for a more equitable distribution and better co-ordination of services and those providing services seek improved working conditions and some guarantee of continuity of funding. The quality of service delivery remains an issue, with recommendations being made to provide for both process and outcome evaluation so that true accountability can be achieved and the needs of children and their families met through a network of co-ordinated and responsive services.

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Chapter 3

EARLY INTERVENTION IN VICTORIA

Timothy G. Moore

INTRODUCTION

The job of presenting an overview of current early intervention services in Victoria is a particularly difficult one. There are a number of reasons why this is so, including increases in the number and range of programs available, changes in ideas regarding delivery of services, transfers of key early childhood services between Government Departments, and a potentially important interdepartmental review of specialist services which has not quite completed its business. Each of these factors will now be described in more detail.

First, there has been such **growth in the number and range of programs** over the last few years that even listing current services becomes a formidable task. The last overview of services (Watts et al., 1981) dealt with the 1979-1980 period and managed to list all the early intervention services then available in Victoria in less than two pages. Many more pages would now be required and indeed it would be difficult to produce a definitive list as there is no central register of services. The present overview cannot hope to be exhaustive, therefore, but will indicate the general scope of available services and give some idea of current problems in the provision of services.

Besides growth in the actual number and range of services available, there have been **significant developments in the general approach to the delivery of specialist services** in recent years. These changes have come from several different sources, including parents, professionals and politicians. Increasingly, **parents** have asked for a greater say in the way services are delivered and in decisions being made about their children. Some parents of children with disabilities have also been asking for resources to be provided to enable their children to attend the same educational and community facilities as their non-disabled peers. The thinking of **professionals** has also changed, with key principles such as normalisation, non-categorisation and integration becoming more widely accepted. Finally, politicians have insisted that practice change in keeping with new policies. Following the 1982 State elections, reviews of various services to children and others were undertaken in order to determine how the newly-elected Labor Government's policies could be translated into practice. These reviews included the Review of Early Childhood Services (1983), the Review of Educational Services for the Disabled (1984), and the Committee on a Legislative Framework for Services to Intellectually Disabled Persons (1984). As yet, only the last of these reviews has led to changes in legislation, but all have, to a greater or lesser extent, influenced both policy and practice in the delivery of human services.

It is not yet clear what effect the legislation referred to (the **Intellectually Disabled Persons Act** 1986) will have on early intervention programs. The Act requires that certain services be provided for intellectually disabled persons but children cannot be registered as intellectually disabled until the age of six. Whether there is a comparable obligation to provide services to all developmentally delayed children below the age of six remains to be seen. Another problematic aspect of the Act is that segregated centre-based services are to be avoided. Yet many existing early intervention agencies offer some centre-based programs and many workers in the field feel that such an approach best meets the needs of at least some children and families. The debate about this issue is bound to continue for some time.

All of the reviews mentioned above made some recommendations concerning services for young children with disabilities and impairments, but these recommendations were often inconsistent with one another and hence were not acted upon. It was not until late 1985 that an interdepartmental **Working Party on Specialist Child and Family Services** was established to resolve some of these inconsistencies and to propose ways in which specialist services, both government and non-government, could be more effectively co-ordinated. This committee, commissioned jointly by the Ministers for Community Services, Health and Education, submitted its final report in August 1986.

One important factor prompting this interdepartmental review was the transfer in 1985 of a number of early childhood services from the Health Department to Community Services. The services transferred included the Office of Intellectual Disability Services (formerly Mental Retardation Division), Child Development and Care Services (including preschools), Infant Welfare Services, Visiting Child Health Nurses, and Early Childhood Development Program Co-ordinators. These transfers had the effect of giving Community Services principal responsibility for provision of both universal and specialist early childhood services. However, the transfers inevitably created a number of problems with some of the services affected having to establish new roles and new relationships with one another. For example, the **Early Childhood Development Program** had been split, with the allied health staff remaining with the Health Department while the co-ordinators and the Visiting Child Health Nurses transferred to Community Services. A new role for the co-ordinators needed to be found and their relationship with the Office of Intellectual Disability Services Early Childhood Teams redefined. It was partly to resolve some of these specific issues that the Working Party of Specialist Child and Family Services was established.

We have just been considering a number of factors which contribute to the currently confused state of the early intervention scene in Victoria and which make it difficult to list and describe all services currently available. In order to compensate for the inevitable sketchiness of any overview, the early intervention scene will be described from two angles. The first will look at key aspects of early intervention provision to see what the major problems in service delivery are, while the second will summarise available services in terms of the specific disabilities catered for.

PROBLEMS IN SERVICE PROVISION

Three key aspects of early intervention provision will be considered in turn to see what problems there are in each area. The three areas to be considered are **early identification, referral and assessment**, and **service delivery**.

Early Identification

The first step towards obtaining effective early intervention services for a child with a disability or impairment is to have the child's needs recognised at as early an age as possible. When surveying the early intervention scene, therefore, we must ask what system exists for identifying children in need of early intervention and how effective that system is.

Obviously, some children who will need early intervention (such as those with Down's syndrome or spina bifida) can be identified at birth. There is nothing to indicate that these children are not being quickly identified in Victoria, and indeed permanently maintained registers of children with congenital impairments have been or are being established (eg. the Congenital Malformation Register). There are other children (such as those of low birth weight) who can be identified at birth as being at risk of having developmental problems. In Victoria, all children of very low birth weight (below 1200 grams) are followed up routinely through the major hospitals. However, whether the process of monitoring such children or of registering those with congenital impairments always leads to the provision of appropriate early intervention is unclear.

There are still other children whose developmental disabilities may not become evident for some time after birth. This group includes those with hearing impairments or with developmental delays. These children are sometimes not identified as early as they might be. The problem is that no formal screening is done in Victoria until children start attending kindergartens at the age of four. Moreover, since not all children attend kindergarten, it is not until children reach compulsory school age that the entire population can be screened. Therefore, the prompt identification of younger children in need of specialist help depends upon parents, infant welfare sisters, and general practitioners/paediatricians identifying children with developmental problems. This process is probably most effective with children below the age of 18 months, since up to 95% of parents take children of this age to an Infant Welfare Centre regularly. However, after children reach 18 months or so, the number who are seen by Infant Welfare Sisters drops off sharply and the prompt identification of children with developmental problems becomes increasingly less efficient. No formal evidence exists regarding the numbers of children who are disadvantaged thereby, but both parents and early intervention agencies are still able to cite instances where the developmental problem should have been identified earlier.

We should not leave the topic of early identification without mentioning the **Early Childhood Development Program**. This program provides a service to the whole community rather than to special needs children alone. However, part of its original brief (Best & McCloskey, 1978) was the early detection of children who, for whatever reason, might have developmental problems. As things stand, the Early Childhood Development Program's capacity to fulfill this brief has been limited by at least two factors. One has already been mentioned: last year, elements of the Program were transferred from Health Department to Community Services, making the future role of the service unclear. A second limiting factor is that the Early Childhood Development Program was never fully established in the first place, with some regions having no E.C.D.P. teams at all. It is to be hoped that the Working Party on Specialist Child and Family Services mentioned earlier will define a clear role for the Early Childhood Development Program (or some program like it) to play in the early identification of children with impairments and disabilities.

Linked with the problem of early identification is the question of just how many children might need early intervention. No definitive epidemiological surveys of the range and incidence of special needs in pre-school children has been done in Victoria which makes it difficult to know precisely what services are needed or how many children might not be receiving services (or only receiving inadequate services). Based on figures quoted by the Commonwealth Schools Commission's Advisory Group on Early Special Education (1985), there should be around 14,000 Victorian children below the age of six who need specialist help, about 10,000 of whom would fall into the category of mild intellectual disability. Although there is no hard evidence for this, those familiar with the early intervention scene feel that nothing like this number are actually receiving services. If this impression is valid, then there is cause for concern about the ability of existing services to meet the need, although it should be noted that a significant proportion of young children with mild developmental disabilities may be catered for quite adequately by the universal services (such as playgroups and kindergartens).

The only evidence so far available regarding the question of numbers comes from a recent survey in the Goulburn-North-Eastern region of the incidence of 0-18 year old children with disabilities and impairments (White 1985). However, this survey only identified those already known to services and was thus unable to establish how many young children were receiving no services at all or only receiving inadequate service. White's conclusion was that the actual incidence of disability was probably much higher than his figures indicated.

Evidence which will help resolve these questions is currently being gathered by the **Early Special Education Needs Project**. This Project, which is funded by the Commonwealth Schools Commission and supported by the Ministry of Education's Integration Unit is attempting to identify all pre-school children in the State who have developmental problems and to describe all the early intervention services available to them. Although the prime aim is to conduct an epidemiological survey, the Project also hopes to identify ways in which the data gathered can be permanently maintained and updated, thus providing a database for use by both government and non-government agencies for planning and co-ordinating the delivery of early intervention services.

Referral and Assessment

Once children with a known or suspected developmental problem have been identified, they need to be referred to an appropriate agency for assessment and/or intervention. The next question to ask, therefore, is how effective is this process of referral and assessment. In other words, are there undue delays between the identification of a known or possible developmental problem and the provision of appropriate intervention? Such delays can easily occur, either as a result of shortage of appropriate programs, or because the identifying person is unaware of existing sources of help.

It is difficult to comment on the question of whether there are significant shortages in the provision of early intervention programs in Victoria at this point in time. This is partly because, as already mentioned, it is not known how many children might need such services, and partly because the rapid growth of services in recent times has not occurred in a co-ordinated way and there is no central register of services now available. However, it is clear that some services at least are inequitably distributed across the State. As has already been mentioned, Early Childhood Development Programs do not exist in some regions. The strength of services provided by other agencies, such as the Office of Intellectual Disability Services, varies from region to region. Thus, although it is not known how many children are not getting the services they need or are only getting partial help, it seems likely that the figure will be a significant one.

With regard to the second question of whether those who identify children in need of specialist help know where to refer them, there are definite problems, at least for some services. Because of the rapid yet unco-ordinated way in which early intervention services have grown in recent times, it has been difficult for those who first identify young children's developmental problems to keep up to date. This is much more of a problem for children with general developmental delays or multiple disabilities than for those with a single well-understood impairment (for example, of hearing or vision). In the latter cases there exist well-known agencies which cater for the specific disabilities and to whom referrals can promptly and easily be made. Thus, young children with a known visual impairment will generally be referred directly to the **Royal Victorian Institute for the Blind** which is the major service provider in this area. For young hearing-impaired children, the position is somewhat more complex as several early intervention services exist. However, initial referrals at least can be made directly to an Ascertainment Committee at **Camberwell Special Education Centre** which has the job of informing parents of the range of services (both Government and non-Government) available and helping them choose an appropriate program for their child. (The future of this particular service, which is run by the Ministry of Education, is currently under review).

Referral procedures for children with developmental delays or multiple disabilities are less well organised and many parents experience significant delays before they find appropriate programs for their children. In an effort to overcome this problem, **Early Intervention Referral Committees** have been formed in most Melbourne metropolitan and a number of country regions in recent years. These Committees are made up of representatives of the key early intervention services in the region and act as a focal point for referrals of children in need of early intervention. The core services represented are usually those provided by the Departments of Community Services (Office of Intellectual Disability Services), Health (Early Childhood Development Program) and Education (Student Services) as well as major non-Government agencies (Yooralla Society, Spastic Society). The Early Intervention Referral Committees have had some success in simplifying the referral process but have been hampered by various problems such as lack of publicity. However, perhaps the major weakness of these committees is that they are informal and lack the official endorsement and commitment of the agencies and Government Departments represented. This is a major drawback and it is to be hoped that more formal structures will be established as a result of the Working Party on Specialist Child and Family Services previously referred to. As they are currently structured, Early Intervention Referral Committees tend to be rather fragile organisations which work well when the individual members agree upon aims and procedures and have learned to trust each other but which tend to fall apart rapidly if there are too many changes of membership.

Service Delivery

The next stage after identification and referral is actual service delivery. Here, the problems are three-fold: shortage of services, lack of co-ordination between services, and inconsistencies in philosophy of service delivery. The question of **shortage of services** has already been mentioned: it is unclear just how many children and families are being disadvantaged by lack of services. What is clear is that there is probably no agency currently able to offer all components of an early intervention program as required, i.e. both centre- and home-based services, multidisciplinary specialist assistance, integration support, respite care, other family support services and so on. It seems likely therefore that many children are being disadvantaged through the inability of existing programs to offer comprehensive services. This places parents in the position of having to use more than one service and it is here that **lack of co-ordination** between services becomes a major problem. Typically, individual early intervention agencies, both Government and non-Government, have tended to plan and provide services with little reference to those provided by other specialist agencies or departments, let alone those provided by the universal services. In practice, this puts an extra burden on parents who may receive conflicting advice from different agencies about how best to meet the child's needs. Some effort has been made to overcome these problems through the establishment of regional committees of early intervention agencies such as the **Shrublands Association** in the Inner-Eastern region or the **Early Childhood Development Resources Group** in Gippsland. Early Intervention Referral Committees also seek to co-ordinate service delivery to individual children but again with limited success. These attempts to coordinate services seem to work more effectively in country regions but all are hampered by the lack of formal structures for planning and delivering services on an inter-agency basis and ultimately by the lack of an overall Government policy regarding early intervention. The current situation regarding the delivery of early intervention services in Victoria is chaotic in many ways and there is an urgent need for both overall policy and planning structures. Again, it is to be hoped that moves in this direction will be made shortly.

The third problem concerns **philosophical differences regarding service delivery**. The fact is that there is not always unanimity within the early intervention field as to the best way to help young children with disabilities and their families. For example, parents of young children with hearing impairments may be faced with conflicting arguments about the merits of an oral/aural approach vs. approaches which rely on argumentative communication, with different agencies taking different stands. Another problem which may face parents is that there are differences of opinion within the field as to the desirability of centre-based programs, with some agencies taking the view that services should be delivered in the home or in a mainstream community setting and that centre-based programs are undesirable. However, many existing services, particularly those for specific disability groups, are centre-based and these often have strong support from both parents and professionals. This is particularly so in the case of low incidence disability groups, such as autism, hearing and visual impairments, where it is unclear as yet how specialist services to these children can be delivered locally. Many feel that some measure of centralisation will need to be retained.

Another problem is that even the policies of different Government services may not be congruent. Thus, the Ministry of Education's policies with regard to the integration of children with disabilities into regular schools guarantees parents the right to have their child placed in a regular school if they so wish. They do not have the same right with preschools, even though there has been a long-standing policy of reserving two places in each kindergarten for children with special needs. However, the Directress and Committee of Management of the kindergarten have the final say and children are therefore not guaranteed a place in the kindergarten of their parents' choice. Increasingly, kindergartens are asking that appropriate support be provided before they will admit children with special needs, and this is often not available, even though Community Services does fund nearly fifty Visiting Preschool Teachers whose main function is to provide such support.

The three problems just discussed are not the only ones that could be mentioned. Two other problem areas include **funding** (which lacks co-ordination and is often too short-term) and **training for early intervention workers** (there is no generic course specifically for workers in the early intervention field and many of the specialist courses lack adequate early childhood components). However, there is not space to consider these in detail.

We will now take a look at the early intervention scene from a different angle, summarising the services available in Victoria. The account that follows cannot hope to be comprehensive, but is intended to convey something of the range of services currently being provided. The services are grouped according to the disabilities catered for, but it should be noted that some services have become less rigid in recent years about applying strict eligibility criteria. **The Royal Victorian Institute for the Blind**, for instance, does not require that all the children it services should be legally blind, but accepts any child who would benefit from the programs provided. Similarly, the **Spastic Society** no longer insists that all the children it services have a diagnosis of cerebral palsy.

AN OVERVIEW OF CURRENT EARLY INTERVENTION SERVICES

Services for Autistic Children

There are four centres catering for autistic children, three in the metropolitan area and one (Mansfield Autistic Centre) in the country. Two of the metropolitan centres (**Irabina** and **Western Autistic Centre**) are funded by the Office of Intellectual Disability Services, while the third (**Mentone Autistic Developmental School**) is the responsibility of the Ministry of Education. Mansfield provides a home-visiting service while the other three centres run centre-based programs and provide support to autistic children being integrated into mainstream settings. All four services cater for school-age children as well.

Services for Visually-Impaired Children

The main agency here is the **Royal Victorian Institute for the Blind** which provides a variety of services, including a home advisory service for children below the age of 3 years 6 months, which currently sees about 135 children across the State. Other outreach services include a visiting preschool teacher and a consultancy service to other agencies working with visually impaired children. R.V.I.B. also has a residential unit and runs centre-based preschool groups. An interesting recent development has been the establishment of integrated preschool groups in community settings. Each group includes three children with visual impairments and twelve others, with an R.V.I.B. teacher working with the regular kindergarten teacher and her assistant.

Another agency catering for visually impaired children is **St. Paul's School for the Blind** which provides a small home-advisory service for very young children and a centre-based program for older children. Finally, there is the Ministry of Education's **Visiting Teacher Service for the Visually Impaired** which supports some preschool children in mainstream settings.

Services for Hearing-Impaired Children

Early intervention programs for young hearing-impaired children and their families are provided by **Taralye** (run by the Advisory Council for Hearing Impaired Children), **Monnington Centre** (Ministry of Education), **John Pierce Centre** (Catholic Education Office) and **Parent Advisors for the Hearing Impaired** (Health Department). All these services differ in their approach to intervention with young hearing-impaired children and in their mode of service delivery. The first three agencies listed run centre-based programs while the Parent Advisors for the Hearing Impaired are based in selected regions and provide a home-based service. Monnington also provides some home-based services to families in metropolitan and country regions which do not have Parent Advisors. The role played by Camberwell Special Education Centre in helping parents choose one of these services for their children has already been mentioned.

The Ministry of Education also provides two other important services for preschool hearing impaired children. First, there is the **Visiting Teacher Service for Hearing Impaired Children** which supports children attending regular kindergartens. Second, there are two preschools exclusively for hearing-impaired children from the age of 3 years 6 months (**Princess Elizabeth Junior School** and **Furlong Park School** for the Deaf). Princess Elizabeth has residential facilities enabling it to cater for children from geographically remote areas.

Services for Physically-Disabled Children

Services for young children with physical disabilities are provided by **Spastic Society**, **Yooralla Society**, and the Health Department. Despite its name, the Spastic Society does not restrict its services to children with a diagnosis such as cerebral palsy but caters for any child who would benefit from an early intervention program which focuses particularly on motor development. Nearly all of the Spastic Society's eleven Day Centres run such programs, seeing a total of over 250 children state-wide. The services offered vary but include individual therapy, playgroups (usually centre-based), preschools (**Shannon Park** in Geelong and **Pennyweight Park** in Ballarat), and support services for children being integrated into mainstream settings. The Shannon Park program (which caters for over 60 children) has a particularly well developed integration support service. **Yooralla Society** has four centres, all in the Melbourne metropolitan area. All run centre-based playgroups for children under 3 years of age and three also have preschools for children aged 3 to 6 years. As with the Spastic Society, there is a trend towards providing services more in the context of mainstream settings. Yooralla Society also employs a number of community workers, some of whom are based in the country, but certain country areas (such as the Mornington Peninsular) are not well covered by either Yooralla or the Spastic Society.

Both these Societies, although autonomous, get the bulk of their funding through various government sources. A service provided directly by the State Government is the Health Department's **Itinerant Physiotherapy Service**. Although not exclusively an early intervention service, about 70% of the work of the 15 or so (equivalent full time) physiotherapists currently employed is devoted to young children. The service receives over 1000 new referrals a year and staff provide domiciliary or local consultative services with a small treatment component. The future deployment of this service is currently under review.

Another program which caters for motor disordered children is the recently established **Tongala Conductive Education School for Parents**. This uses the conductive education system developed in Hungary by Andras Pewto, and caters for over 20 children. Interest in this program and in the general approach appears to be growing rapidly.

Although not specifically for young children with physical disabilities, two other programs should be mentioned here because of the heavy emphasis they place on physical modes of intervention. These are the **Institute for the Achievement of Human Potential** and the **Australian Centre for Brain-Injured Children**. Both these services are fee-paying and require a tremendous commitment in terms of time and effort on the part of the parents. Both rely on the Delacato theory that neurological disorders can be remediated through intensive sensory and motor stimulation programs. This approach has not gained general acceptance in the early intervention field, both because of concerns about the heavy demands it makes upon parents and because of lack of convincing evidence for its effectiveness (Nettleton & Bradshaw, 1982).

Services for children with language disabilities

There are two programs specifically for children with language disabilities: one is based at the **Lady Gowrie Child Centre** (Nowotny & Blondel, 1982) while the other operates under the auspices of the **Education Faculty at Monash University**. Both programs cater for relatively small numbers of children only.

Services for children with Intellectual disabilities or developmental delays

Most early intervention services in Victoria fall into this category and it is here that the greatest problems lie in providing a complete list. The services can be loosely grouped according to whether they are non-categorical (that is, cater for any children with special needs, regardless of the nature of the disability) or are intended specifically for children with intellectual disabilities.

Key non-categorical services include **Noah's Ark Toy Library** and the **Early Childhood Development Program**. The current confusion surrounding the future role of the latter service has been mentioned already. Noah's Ark Toy Library is an important program because it provides services to a large number of families and is the first agency that many parents have contact with. The actual services offered are much broader than the name toy library suggests and cover a whole range of family support programs, including playgroups, sibling groups and holiday programs. Noah's Ark is based in Windsor but has bases at the Royal Children's Hospital and Footscray as well as six autonomous branch libraries in key country centres. All branches have mobile units to enable them to visit the more isolated families. Another important non-categorical service is provided by the **Visiting Preschool Teachers**. Funded by Community Services but employed by local councils or other agencies, these teachers support children with special needs who are attending regular kindergartens.

There are many other non-categorical services, mostly individual programs serving a particular geographical area. Some have been running for some time but many new services have been established relatively recently. The programs vary considerably in the range and kind of services they can provide and many are not yet funded on a permanent basis, making it difficult for them to maintain services to children and families at a constant level. Metropolitan-based programs include Biala (Box Hill), STRIDE, Waroogah, Biala

(Ringwood), The Patch Early Intervention Program, Mooroolbark Early Intervention Program, Chandler Early Intervention Program, Norparrin, Handihelp Brunswick, Malvern Playgroup, Waverley Special Needs Playgroup, Uncle Bob's Kindergarten (Royal Children's Hospital) and the Krongold Centre for Exceptional Children (Monash University). In addition, there are early intervention programs in many country centres, including Geelong, Colac, Warnambool, Churchill, Bairnsdale, Sale, Kilmore, Seymour, Corryong, Benalla and Wangaratta.

As mentioned earlier, there are other programs which were, originally at least, set up specifically for children with intellectual disabilities. These include services provided by the **Office of Intellectual Disability Services** (O.I.D.S.) and early intervention programs attached to **Day Training Centres** (which are funded by Community Services) and **Special Developmental Schools** (which are run by the Ministry of Education). In recent years, admission criteria for these programs have broadened, and increasingly they have catered for children with a variety of special needs. Indeed, it seems possible that the brief of the O.I.D.S. Early Childhood Teams will soon become the provision of various specialist services to all children with developmental disabilities. These multidisciplinary teams can be found in each region, their strength varying according to what other local early intervention programs are available. In the Westernport region, the O.I.D.S. team provides a complete early intervention program (**Step Ahead**) in its own right, but most regional teams concentrate on a mixture of direct service and consultant support to other agencies. Although there is a preference for home-based services, O.I.D.S. still funds nine Day Training Centres which run centre-based programs. Two of these programs (**Broad Insight** and **Kalparrin**) are exclusively for preschool children and others (**Irabina** and **Western Autistic Centre**) only cater for children deemed autistic. The number of Day Training Centres funded by O.I.D.S. has dropped steadily over the years with many of them opting to transfer to the Ministry of Education as **Special Developmental Schools**. About half of the 36 Special Developmental Schools run early intervention programs, but these are usually small in scale and vary in format. Most are centre-based although a few (such as **Cobram S.D.S.** and **Moorabbin S.D.S.**) concentrate entirely on providing home-based or integration support services.

Another significant program that should be included here is the **Educational Program for Infants and Children** (EPIC) based at Phillip Institute of Technology (Clunies-Ross, 1976). This program caters for over 100 Down Syndrome children and concentrates on providing centre-based structured teaching sessions for individual children with a primary aim being preparation for integration into regular schools. This well-established program has been one of the few to publish studies of its effectiveness (Clunies-Ross 1979, 1981; Hudson and Clunies-Ross, 1984).

PROGRAMS OF SPECIAL INTEREST

There are a number of interesting early intervention projects and programs which have recently been initiated in Victoria. One which has been mentioned already is the Early Special Education Needs Project. Three others will now be described briefly.

> **Early Intervention Resource Unit** was established in 1984 within the Mental Retardation Division (now Office of Intellectual Disability Services). The Unit has a dual function: to provide regional early intervention services to 0-6 year old developmentally

delayed children, and to function as a specialised resource and training service for early intervention agencies, both government and non-government, across the State. The Unit is in fact one of the twelve O. I. D. S. Early Childhood Teams but has been given extra funding and staff to perform its additional resource and training function. Although the E. I. R. U. has been hampered by inadequate funding, it has managed to produce several excellent videos (with more to come) and represents an important step towards recognising the specific needs of workers in the early intervention field.

Formed in 1985, the **Early Intervention Association of Victoria** represents both parents and professionals interested or involved in early intervention work. In the short time it has been established, the E. I. A. V. has run a number of workshops, sharing sessions and a short training course for members as well as taking on the role of lobbying for improved services. What is noteworthy about this Association is how rapidly it has grown, suggesting that it is meeting a real need among early intervention workers to share their knowledge and concerns, and that the early intervention field in Victoria is developing its own distinct identity.

Self-help and advocacy groups

The early intervention scene would not be complete without some reference being made to the developing role of such self-help and parent advocacy groups as Action Group for the Disabled, STAR Victorian Action on Intellectual Disability, Parent-to-Parent, Community Based Educational Resource, and Action on Disability in Ethnic Communities. Although none of these bodies deals exclusively with preschool children, they do offer a variety of support, counselling, information-giving and direct advocacy services to parents that can be invaluable and often cannot be duplicated by professionals.

CONCLUSION

From the overview that has just been presented, it can be seen how diverse and fragmented early intervention services in Victoria are. Three government departments provide services in addition to a plethora of independent agencies, both large and small. Forms of service delivery vary considerably and no consensus has yet emerged as to the most effective mode of early intervention.

Co-ordination of service delivery and development of an overall policy regarding early intervention would be facilitated greatly if a single government department were identified as being responsible for this area. Following the recent transfers between departments of key early childhood programs, Community Services looks like the best candidate for this role and there is the possibility that this will be consolidated further by other transfers. The Ministry of Education seems to be reviewing its involvement in early intervention, and agreement was recently reached that early intervention programs attached to Special Developmental Schools would become the responsibility of Community Services at some stage yet to be determined. Again, the response of the Ministers to the report of the Working Party on Specialist Child and Family Services should clarify the overall picture.

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Chapter 4

EARLY INTERVENTION IN QUEENSLAND

Gerald Ashby and Jeremy Taylor

The development of special education services for children below school age in Queensland has been substantially influenced by policies and provisions of the Department of Education. As is the case elsewhere in Australia the earliest provisions were categorical and consisted of services for children with hearing, visual and physical disabilities. In general terms these services were restricted to Brisbane and only a few other centres. However, since 1973, when the Department of Education began implementing a major program of preschool education, a series of more wide ranging provisions have developed.

Over the period 1973 to the present, three specific stages can be identified. These are the periods 1973 to 1978, 1979 to 1984 and 1985 onwards. Each stage is associated with the introduction of a particular policy which set a scene for specific initiatives. The development of new services and expanding ideas can be traced by reference to a considerable documentation, chiefly published by the Department of Education.

Before considering the three phases in more detail, it will be useful to note three other matters which help to explain the developments. First, the development of State preschool facilities, which complemented the work of the long standing community preschool movement, resulted in the establishment of an extensive network of early childhood services throughout the State. The range of facilities included both traditional preschools plus non-traditional approaches such as provisions in small rural communities and a preschool correspondence service for geographically isolated families (Ashby, 1980). By 1986 the system had established more than 880 facilities and was catering for approximately 75 per cent of all four to five year old children in the State with the community movement catering for approximately a further 15 per cent of all three to five year olds. The infusion of a distinctive 'early childhood education' philosophy extensively throughout the State provided a catalyst for raised awareness concerning the needs of and services for very young children and for the introduction of many local initiatives.

Second, from the late 1970's onwards, following the establishment of a Cabinet Committee consisting of the Ministers for Health, Education and Welfare, extensive work was undertaken at an officer level to reduce communication problems which plagued efforts at interagency and interdisciplinary co-operation. The formation of a policy of decentralisation of decision making, by which medical and health professionals, educationists and welfare professionals were encouraged to seek local solutions to needs, created new opportunities in providing services for young disabled children (IDSC-HEW, 1982; Ashby, 1983). While there is evidence that the quality of services fell short of what is required (QPD, 1981) there is also evidence that the positive interaction between agencies provided a significant platform for service delivery.

Finally, over the period extensive changes were introduced in the organisation and delivery of special education services in Queensland. Two particular developments should be noted. First, decentralisation through the devolution of decision making to educational regions strengthened the role of regional officers in responding to identified needs. This process was extended by the further devolution to subregional teams (i.e. districts) with explicit encouragement to develop local responses. In the process resources were transferred from central control to regions and districts. While the relationship of this development to early intervention may not immediately be evident, it was nonetheless a decisive factor in creating new services, especially for the very young. The second factor involved a substantial change of direction in the roles of 'special schools' away from specific target groups (chiefly the 'mildly intellectually handicapped') to serve the needs of a wider and more disabled population. This process was accompanied by the general thrust towards integration which refocused attention on the arbitrariness of providing segregated services for disabled children of compulsory school age.

1973-1978

Draft rules for the operation of State preschools were tabled in the Queensland Parliament in 1972 and contained the following provisions:

> Up to 20% of places in any centre may be reserved from time to time by the Director of Preschool Education for the admission of children with special educational needs; preference will be given to children with handicaps referred by the Director of Preschool Education on the advice of the Director of Special Education. In instances where a centre, receiving a referral for special admission of a child with a handicap has already the maximum enrolment of 25 children per group the teacher may elect to enrol up to two such children provided:
>
> (i) the teacher is of the opinion that such an increase in the enrolment will not decrease the efficiency of the preschool program; and
>
> (ii) if vacancies occur during the year the total number enrolled in each session will be brought back to 25 children.
> (Department of Education, 1973)

These provisions created an opportunity for disabled children, within the eligible age range for preschool attendance (i.e. 4-5 years), to gain admission to preschools. Between 1973 and 1978 some 331 preschools were opened providing approximately 21,000 places. Included were a number of specially designed facilities for the hearing impaired in areas where there was an urgent need for this service. The net effect was the admission of increasing numbers of children identified by guidance officers as having some special educational needs.

A study of all special admissions to regular preschools between February 1977 and July 1979 in one Brisbane educational region was conducted by Nathan and Sultmann (1981). They reported that during the sampled period a total of 295 special admissions were made which represented 2.5 per cent of the then preschool enrolments for the region. The study identified a number of issues which were of importance in shaping future policy. First, it was found that the largest proportion of children (61%) were not assessed for disability until between 49-60 months. In fact about one third of all cases were initially referred to guidance officers by preschool teachers. Further, it was noted that upon assessment about two thirds of the group were identified as having at least four significant deficits. These were typically in the areas of language, speech, socialisation, fine and gross motor skills and concept development. However, a total of 17 disabling conditions were recorded. Of greater importance was the fact that a large number of special admission children were not assessed beyond the initial assessment and further, that, for two thirds of the group, parents were only interviewed on one occasion. It was also shown that a large number of agencies, both Government and non Government, could be involved with a child and the family at the same time.

The issues raised by the study were significant. First, it was apparent that in a number of cases, identification occurred later than desirable. Second, that if preschool placement was to assist the child and the family, a higher level of communication between the various people involved and between agencies had to exist. Third, that a more acceptable level of support was required for preschool teachers and parents.

The provision of special admission into regular preschool represented one level of early intervention. However, Nathan and Sultmann also revealed that a number of children presented very complex conditions, and delay of services until four or five years of age was inadequate. Thus, it was essential that a further form of provision be explored. This was the focus in the second stage of development.

1979-1984

During the period 1979-1984 certain of the promises implicit in policies initiated earlier came to partial fruition. A more substantial commitment was made to the provision of early intervention. By the end of the period the Department of Education had come to be viewed as the prime agency for the delivery of early intervention programs. In certain respects the process of developing a systematic provision of early intervention in Queensland reflected that of an action research cycle. A commitment was made to formative evaluation (see Hayes et. al. 1981) and the multiplicity of committees, whose activities are discussed in this section, indicate a process characterised as responding to problems as they emerge in practice.

In 1979 the Division of Special Education extended its work in the preschool area by establishing a pilot network of preschool services for young children with disabling conditions. The pilot program, termed early educational intervention, represented a policy response to the considerable body of research, primarily overseas in origin, as well as professional and parent views. The pilot projects operated predominantly in preschool centres with, however, one continuing project operating out of a special school.

Four principles were distilled as key elements of early educational intervention programs. These were set out in an information statement published by the Division of Special Education. They were:

- provision of planned education from the earliest possible age;
- close involvement of parents and family in the education process;
- keeping a wide range of educational options open for the child;
- maximising the opportunity of the child to experience a wide range of behavior models

(Ashby, Cliffe, Culbert & Miller, 1979:pp.3-4)

The program was seen as consisting of two components; a home-based phase from birth to three years of age, and a centre-based program for children between three and five or six years of age. The projects aimed to cater for children with

> developmental problems which are considered likely to interfere with their later school progress. These problems may be associated with physical, intellectual, speech and language, neurological or emotional development.
>
> (Ashby et al, 1979:pp.10-11)

In the information statement the issue of combined medical/therapeutic services and educational/developmental activities was addressed. The pilot projects were viewed as involving transdisciplinary teams and teacher collaboration with agencies providing specialised services. The need for coordinated services emphasised the requirement for a key person to be designated. The information statement also outlined the overall philosophy and provided broad guidelines for the development of early educational intervention programs that were sufficiently flexible to allow different interpretations by teachers with varying educational backgrounds and philosophies.

The pilot projects were subject to a complex monitoring process by a team from the Fred and Eleanor Schonell Educational Research Centre (Hayes et al, 1981). After two years of operation, researchers from the Schonell Centre commented:

> The future course of development of special preschools in Queensland will initially depend on the establishment of effective networks of communication.
>
> (Hayes et al, 1981:p.143)

This comment reflected the concerns of the monitoring team with problems that had arisen concerning communication between projects and families, and teachers and the providers of specialised services. In particular, the monitoring team noted many problems associated with assessment and record keeping and that this, in turn, caused problems in implementing the principle of non-categorisation. Thus, despite a commitment to non-categorisation

> . . . groups within special preschools were formed on the basis of single characteristics of the children (such as degree of intellectual handicap or language delay).
>
> (Hayes et al, 1981:p.143)

The monitoring team argued that this practice reflected the limited assessment data available to preschool teachers which increased the risk of inappropriate labelling. These problems reflected the serious shortage of personnel with appropriate training and experience in assessing young handicapped children. The monitoring team also noted differences in record keeping between the different elements of the project teams. These differences encompassed variety in content, format, technical language and different policies with regard to information storage and retrieval. The tendency was noted for personnel involved in assessment to record formal test results more frequently than informal observations. Further the monitoring team observed that 'Test results were often recorded in a form that was too cryptic for optimal utilisation by teachers and other interveners . . .' (Hayes et al, 1981:p.148)

Teachers in the early educational intervention projects reported that the breadth of the guidelines and the lack of a clearly defined support network placed them under pressure to perform both program implementation and parent support aspects of their role. The monitoring team reported that the problem of limited time and a lack of adequate programatic resources, influenced the role of interveners: 'Gradually, the Departmental emphasis has come to be placed on the teaching role' (Hayes et al, 1981:p.151).

In summary form, the major issues that emerged in the monitoring process included:

- the need for effective communication networks between teaching staff, other professionals supporting the program, other agencies able to provide services to

> children and families, senior Departmental officers (including those of departments other than Education) and parents;
>
> - the clarification of roles of those directly involved in service provision;
> - establishment of appropriate and comprehensive assessment procedures and transfer of information to relevant parties in useable forms;
> - the institution of appropriate methods of assessing the needs of client families in addition to those of children;
> - specific training for guidance officers and teaching staff in developmental analysis and review;
> - encouragement of both home-based and centre-based interventions;
> - specific training for teaching staff in parent counselling, development of parent training; programs of parent involvement;
> - institution of systems which enable guarantees to be given to teaching staff of the availability of specialist consultants and other support programs;
> - establishment of close formal links between 'special preschool services' and regular preschools and kindergartens.
>
> (Hayes et al, 1981:pp.141-169)

It is necessary to place the criticisms made by Hayes et al in perspective. Watts et al. (1982), who undertook a national study of early intervention programs, made the following comment, perhaps in a comparative sense, concerning the development of early intervention in Queensland:

> the degree of co-operation between the various government and voluntary agencies, particularly at the workface, was a noteworthy feature of early intervention emerging in Queensland.
>
> (Watts et al, 1982:p.50)

However, they also commented that much of this co-operation rested upon informal links between professionals working in different agencies, and thus tended to be insecure and subject to fluctuation if team members changed or agency policy changed. These problems of ensuring coordination between agencies were made critical by the fact that the Department of Education was not permitted to employ medical and health care professionals. This was the responsibility of the Department of Health. Further early intervention was being implemented by two departments: both Education and Health. The latter, through its Intellectual Handicap Services Branch, provided characteristically distinct approaches. The issue of coordination was made even more complex by the operation of a number of programs administered by non-government organisations (Watts et al., 1982:p.55).

Each agency presented a distinctive approach to early educational intervention. Intellectual Handicap Services branch saw provision for children with intellectual disability as its prime responsibility and was involved in the delivery of a home-based family support program that provided home visiting by interdisciplinary teams, but did not include teachers. The non-government organisations were primarily involved in the delivery of services to children defined by category of disability. These organisations received funding from both State and Commonwealth Governments for their programs. In this context the Department of Education attempted to develop a complementary service aiming to 'fill the gaps' through the provision of non-categorical early intervention programs. Department of Education programs tended to be centre-based, emphasising the delivery of educational programs in preschool settings. Watts et al (1982) highlighted the difference in provision between the two State departments by reference to the different age groups served. The Department of Education mainly provided programs for children over three years of age (only 21% were younger) while the Intellectual Handicap Services branch provided services to children below three (77% fell into this group).

A parallel development to the introduction of the early educational intervention projects was the establishment of the Inter-Departmental Standing Committee of the permanent heads of Departments of Health, Education and Welfare (IDSC-HEW) to 'oversee the coordination of school-based services offered by the three Departments to children and families in Queensland (IDSC-HEW, 1982). This committee represented a significant advance in dealing with problems of coordination and communication at the senior level of management. Also it provided a forum where such issues could be placed on the agenda for consideration by officers of sufficient status to ensure action on decisions and agreements.

In 1980, this committee established the Interdepartmental Advisory Committee on Early Intervention Programs (IACEIP) with membership drawn extensively from Health and Education as well as Welfare Services. One function of the committee was to 'review existing provisions and policies with the aim of developing guidelines for the coordination of services offered by the three departments'. At about the same time the IDSC-HEW released a model for coordination of health, education and welfare services to schools and children. This document described interdepartmental access at three levels, central office, regional centres and districts (subregional). It also set out the membership and roles of each level. Membership of Regional Coordinating Committees consisted of the Regional Director of Education, the District Officer of the Department of Children's Services, a Medical Officer from the Department of Health (or other senior officers, e.g. the Superintendent of the local hospital) and the Regional Special Education and Guidance Officer as Secretary. The regional group was responsible for the implementation of policy relating to service delivery and provision of advice concerning needs to the central group. The district group was responsible for direct client services (Ashby, 1983).

In November 1982, a process of program development commenced that included participation from a broad range of agencies involved in service delivery and parents' groups. The process commenced with a workshop attended by professionals and agencies involved in service delivery at which issues concerned with service delivery to children and families were discussed. After a further workshop in July 1983, recommendations were forwarded to Interdepartmental Advisory Committee on Early Intervention. These recommendations reiterated many of the concerns relating to communication among professionals, team approaches across agencies, rights of parents, and the use of professional jargon that had been expressed in the report of the monitoring team. In response to the recommendations, a working party was established to consider the ways in which the recommendations might be implemented. The working party subdivided into eight working groups each of which was given a specific area to investigate and report on. The working group approach provided an opportunity for the collaborative modification of policy and practice in the area of early intervention. The groups included representation from various government and non-government agencies involved with service delivery at many levels, and representation from parent groups.

As a combined result of the activities of the working groups, the working party submitted a report to the IACEIP entitled Communication Issues in Early Intervention (IACEIP Working Party, 1984) that made 24 recommendations, most of which aimed at practical means of improving service delivery in early intervention programs. The focus of the 24 recommendations may be summarised by reference to three major areas:

- changes to the formal structures to enable more efficient communication;
- provision of opportunities for communication;
- acquisition of the knowledge and skills required to communicate more effectively.

Further indication of the development of a commitment to systematic provision is indicated in the Third Report to the Minister of Education of the Advisory Council for Special Education (1983). This contains a position statement on early identification of handicap in childhood in which such issues as single event developmental screening and more continuous developmental monitoring were examined. The report argues:

> A surveillance program involving all children with ongoing monitoring of growth and development would have many advantages over isolated developmental screening operations

and

> . . . a climate has to be created wherein parents and the various professionals subscribe to a common view that the child has a right to develop to his (sic) limits. As a consequence, any obstacle or impediment to that achievement of potential, must be recognised and accounted for in a concerned and effective way.
>
> (Advisory Council for Special Education, 1983:16)

The report describes a monitoring process in which different agencies from the medical, welfare and educational sectors cooperate actively to maintain an information flow in order to develop coordinated and effective early intervention procedures. The report also considers communication among professionals and between professionals and parents and argues that plain language should be the norm, with only those terms peculiar and essential to a discipline being invoked.

A review of the period 1979-1984 indicates that it was one in which there was a sustained commitment to the establishment of procedures between agencies to ensure systematic, coordinated provision. Amongst the more important issues confronted was that of effective communication between professionals in different agencies. Concentration on communication issues can be seen as a response to the expanding role of the Department of Education in providing services to young children with disabling conditions. By 1984 the concept of gap filling had been replaced and the Department had assumed the mantle of the agency with prime responsibility to ensure the provision of early educational intervention in systematic form throughout Queensland. These developments complemented the access to regular preschools established during 1972-78.

It may also be noted that amendments to the Education Act in 1984 made sweeping changes in the area of special education. Of particular significance in relation to early intervention was the insertion of a clause which set no lower age for the provision of education services to disabled children so long as the parents of children below compulsory school age gave their consent.

Finally, the central importance of 'education' in early intervention in Queensland was also, if somewhat belatedly, reflected in Federal Government policy towards young children. In 1983 children enrolled in early intervention programs became eligible for Commonwealth Schools Commission assistance through the Special Education Program. In many respects perhaps the most important development in this period was that of a demedicalisation of services to young children that was symbolically represented in language by the insertion of the term education into the expression 'early intervention'.

Post 1984

In 1985 early education intervention in Queensland entered a new phase reflecting growing maturity and sophistication of the service. The information statement issued in 1979 was replaced by a new statement which added one further key principle to the four set out in 1979. This was

> The coordination of services from the various disciplines and agencies that may be involved. (Children may have a range of disabilities requiring the services of a number of professionals. It is essential that these professionals work together to ensure that the child's needs are met effectively and efficiently and without creating unnecessary pressures on the family and child.)
>
> (Division of Special Education, 1985)

The statement went on to describe five levels of service (described as 'placement options'). It also described, in very general terms, the age levels and possible levels of disability for which these options were designed and the primary and other support services provided for each. The placement options presented were:

A home-based program

Regular preschool placement with monitoring

Regular preschool placement with regular defined support

Part time placement in an early intervention program (with possible part time placement in a regular preschool)

Full time placement in an early intervention program.

In addition a program called ISOSEVERE (Isolated Severely Handicapped Children Support Program) was extended to cater for children below school age. This service operates through the use of itinerant personnel and programs are reported in Torres Strait, the Gulf area and a number of other locations (SHEPARD, 1986:17).

The new information statement also set out details of the referral and placement process, including assessment. Principles and procedures relating to programming and program implementation were detailed together with information concerning interagency co-operation and communication. A subsequent statement in the SHEPARD Bulletin (SHEPARD, 1986) set out the services which were to commence during the year. In the process the statement added yet one further key principle of early educational intervention to the five which had already been published. The additional principle was '. . . (to provide) support for parents to ensure that the nature of complementary services is understood' (SHEPARD, 1986:3). This indicates the extent to which those developments which occurred during 1979-1984 had begun to be written into the system.

Further evidence of the process of refinement was provided by the publication of Early Education Intervention : Handbook of issues and strategies (Division of Special Education, 1985). This publication provided information on many areas critical to appropriate program design and management. Included in the publication was discussion and information on such issues as parent involvement, team approaches, assessment and information issues, curriculum issues, instructional strategies, and integration into regular classrooms. It also sets out practical advice by officers from the Departments of Education and Health and may be seen as representing a tangible outcome of earlier efforts to ensure effective communication between medical and educational personnel.

In 1987 the Department of Education operated 39 facilities for children below school age. While the majority of these facilities offered a variety of programs, a number also continued to cater for categorical groups. The term Special Education Development Centre was coined to identify places offering generic services. Departmental officers estimated that in November 1987 a total of 836 individual children were being catered for in these facilities (Personal communication to authors). Further, the Department of Education assumed responsibility for educational services to children and young people to the Endeavour Foundation from 1 January, 1986. This transfer included responsibility for the operation and administration of 10 mobile, transdisciplinary teams providing early intervention services to intellectually disabled children.

In addition the Department of Education operated 765 preschool units and 139 early education classes catering for an estimated 33,204 (as at July 1987) children or 75 per cent of the eligible population (Personal communication to authors). If the estimate of Nathan and Sultmann (1981) referred to previously was sustained, the number of disabled young children receiving additional support in regular preschools would be approximately 800 children. Unfortunately statistics on this aspect of provision are not recorded separately. However, Burge (1984) estimated that special education services were required by 3.1 per cent of the total Queensland school enrolments. If this estimate is reliable and capable of being applied to the below school age population the resulting target would appear achievable.

Thus, the quantitative data available indicates that the Department of Education has not only taken up the mantle of being the agency with prime responsibility for the delivery of service to the below school age population but may also be in a position to provide a form of provision to almost all who, it is currently considered, require early educational intervention services. However, what is not indicated in the quantitative data is the extent to which the Department of Education has been able to develop an infrastructure to ensure sufficiently widespread dispersal of necessary skills required to maintain and improve the quality of provision. The question of maintaining quality of provision is one which becomes critical in systems which have experienced a period of 'fast growth' such as can be seen in the recent history of early educational intervention in Queensland.

Notwithstanding the substantial and sustained commitment of the Department to early educational intervention, there is no doubt that it remains a fragile undertaking. The inability of the Department to directly employ and deploy therapists and other health care professionals makes it reliant upon contributed services. This constrains efficient planning and delivery and affects both the quantity and quality of services. However, it is notable that this limitation is recognised, hence the extensive effort in relation to 'communication' issues, which are fundamental to any transdisciplinary activity.

It is perhaps an indication of both the confidence and the sophistication of the Department's structures that two major objectives were indicated for early educational intervention in 1986: expansion of services for children 0-3 years; and the emphasis given to services for severely disabled isolated children. Further, it was stated that

> it is expected that by the end of 1987 there should be sufficient resources to support the majority of young disabled children from 0-6 years of age throughout Queensland.
>
> (SHEPARD 1986:3)

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Chapter 5

EARLY INTERVENTION IN SOUTH AUSTRALIA

Verity Bottroff

From the outset of this project, it became very apparent that South Australia is in need of an Early Intervention Association. There have been some significant changes in South Australia since the last major Australian report on Early Intervention Programs for young Handicapped Children (Watts et. al. 1981) in particular, the regionalisation of services for children with developmental disabilities within the education, health (including the Intellectually Disabled Services Council), and welfare areas. Such changes have highlighted an urgent need for the coordination of early intervention services at a state level.

Two major reports on the requirements of persons who are intellectually disabled in South Australia have contributed to the changes in the system of service delivery to people with disabilities and their families. The first is the report of the Committee on the Rights of Persons with Handicaps (Bright, 1981). The second is the Intellectually Retarded Persons Project Report (IRPP) (McCoy, 1981). Both of these reports emphasise the 'least restrictive alternative' derived from the normalisation principle (Wolfensberger, 1972) in developing services for people with intellectual disabilities.

The Intellectually Disabled Services Council (IDSC) was established in 1982, as a statutory body of the Health Commission and the primary government agency responsible for the management of services for people with intellectual disabilities and their families. The IDSC has accepted as its broad policy priority, promotion of the right for people with intellectual disabilities and their families to have access to community services, rather than the direct provision of services. The principles and objectives developed by the Intellectually Retarded Persons Project (McCoy, 1981) and endorsed by the South Australian Government have been adopted by the IDSC to guide the future development of services in this state. One of the principles is that:

> Special services and support are necessary to meet the needs of persons with an intellectual disability and should be part of a local integrated and coordinated service system. (IDSC, 1984:6)

This principle gives rise to the following objective:

> to promote the use of generic or general services by persons with an intellectual disability and their families and the acceptance of those persons by those services.
> (IDSC, 1984:8)

The latest Australian report on persons with handicaps (Report of the Handicapped Programs Review, 1985), also focuses on access to generic or mainstream community services.

Nelson (1985) discusses the changing climate for the provision of services for people with disability, emphasising the effects on early intervention services in South Australia. She explains how government policy, and hence funding guidelines, have encouraged the development of small community-based facilities. Very often these programs have been initiated as self-help projects (e.g. the Developmental Learning Programme for young Down Syndrome children) or as off-shoots of established organisations (e.g. Seawinds). Gullywinds and the Southern Early Intervention Centre are financed by the Spastic Centres of South Australia. As a result, many early intervention programs are located in segregated settings offering specialised services to clearly defined client groups.

However, the concept of normalisation places particular demands on these programs. They are being required to provide:

1. opportunities for clients to be integrated into generic services, or for 'normal' children to be involved in the early intervention programs (as occurs in the Townsend Kindergarten, where there is a small number of children with a hearing disability);
2. options for consumers such as home-based or centre-based programs. Nelson acknowledges that the above provisions may provide desirable outcomes for the child with a disability and his/her family but explores the difficulties which are being encountered by many individual programs in attempting to provide such services. The difficulties primarily relate to funding for resources and overall coordination of services.

Inadequate levels of funding for established organisations and voluntary organisations may not make it possible to provide sufficient administrative, clerical or professional expertise to incorporate the desired changes. The quality of the program may be compromised or the support for children using integration options may be limited or even unavailable. Despite the emphasis on use of generic services, very little appears to be forthcoming from these agencies.

> The Coleman Report of 1983 recommended the restructuring of services for children in South Australia to improve coordination of options such as kindergarten or child care. As a result of these recommendations, the Children's Services Office (CSO) was established in July 1985 as a statutory body responsible to the Minister for Education. Unfortunately, the Coleman Report paid little attention to the provision of resources or organisation of services for children with special needs. As a result, CSO is inadequately funded to maintain existing integration programs let alone cope with increasing demands arising from government policy directives for services for disabled children.
>
> (Nelson, 1985:3)

A number of early intervention programs in South Australia need to rely on more than one source of funding in order to function. As most funding is submission-based, there is considerable uncertainty about the continuity of funding on an annual basis and the level of funding may decrease in real terms over subsequent years. Additional difficulties and confusion have arisen due to the Commonwealth Government's recent changes in funding responsibility. Within the last few years some early intervention programs in South Australia have had their funding transferred from the Department for Community Services to the Commonwealth Education Department. With the changes in the system of service delivery, increased attention is needed to establish coordination of developments in the area of early intervention. Numerous programs are being developed by both the private and public sectors which adds to the fragmentation of services. The most obvious need is for coordination at the state level.

With the increasing involvement of generic services there is also an increase in the number of government departments associated with individual early intervention programs. It also needs to be recognised that the senior staff working in individual early intervention programs will require more time for coordination because of the range of personnel involved in the programs. This aspect of coordination has staffing implications (i.e. need for more staff and/or reorganisation of staff roles). In discussions with a number of directors of early intervention programs, the former need is highlighted, due to the **additional** demands associated with the implementation of normalisation principles.

Against this background of change in the system of service delivery to people with developmental disabilities and their families, with no State Early Intervention Association attempting to coordinate the development of services for the younger population, a small group of professionals involved in the area of early intervention met and decided that the most efficient method of obtaining initial up-to-date information would be through a structured questionnaire. The following guidelines were presented to the organisations to assist them in structuring their responses.

1. Nature of disabilities: diagnoses and initial assessments
2. Source of funding
3. Age range of clients
4. Staffing: numbers, background of senior staff, nature of inservice training
5. Historical background of agency/organisation
6. Philosophy of the program
7. Aims and objectives of the program
8. Referral system
9. Model of intervention (theoretical)
10. Levels of interaction and integration with other organisations: support provided
11. Practical programming: assessments, implementations, techniques, evaluation
12. Follow-up system
13. Provision of home support
14. Country services
15. Level of parent involvement:
    - Who among family members participate?
    - What is the nature of their involvement?
    - What are the reasons for their involvement?
    - When do they become involved?
    - Where does their participation take place?
    - How is their participation induced?
16. Difficulties/areas of concern: from both the professional and parent perspective
17. Overall evaluation of the program
18. Future plans.

Thirty contact people/organisations were identified by the professional group, utilising personal knowledge and facilities cited in previous research (Watts et al, 1982). The questionnaires and a covering letter explaining the project were sent and a one third response rate was achieved. More professional time than was available would be necessary for an effective follow-up.

1. Diagnosis and Initial Assessment

For most of the programs the diagnosis and initial assessment usually accompany the referrals which come mainly from one of the Child Assessment Teams at the major public hospitals (e.g. Adelaide Children's Hospital, or Flinders Medical Centre), the Child

Adolescent and Family Health Services (CAFS), Intellectually Disabled Services Council (IDSC) or individual professionals (e.g. medical practitioners, psychologists, speech Pathologists, physiotherapists, occupational therapists) as well as parents themselves. In the area of autism, a written referral from a relevant professional who suspects that the child may be autistic, is made to the Executive Director of the Autistic Children's Association of South Australia. The child is then assessed by the appropriate professionals within the organisation. If diagnosed as autistic, the child will be offered a placement in the early intervention program when resources are available.

The Down Syndrome Association of South Australia have a Hospital Visiting Team and the introduction of parents and children with Down Syndrome to the Association is usually through hospital visiting by parents who are members of the team. These visits take place as soon as the new parents express the desire for contact with other parents. The Hospital Visiting Team has found that most new parents do wish to speak to other parents within a couple of days of hearing the diagnosis. When parents then feel ready to seek additional information regarding the early education of their child, they are able to contact the Director of the Developmental Learning Program.

2. Programs and Service Delivery

The **age range** of clients in the early intervention programs is usually from birth or age of diagnosis to kindergarten or school age (5-6 years) and children are placed in normal kindergartens and schools wherever possible. Both the Children's Service Office and the Education Department have professional support staff to assist children requiring **integration** support. However, the number of children needing help is becoming increasingly disproportionate to the number of staff available in the generic services to offer the necessary assistance. Hence a number of early intervention programs are seeing the need to widen their services and incorporate more integration support (e.g. the Down Syndrome Association have recently employed Integration Teachers in their Developmental Learning Program). The one exception in this area is the Autistic Children's Association of South Australia (Inc) which has, since 1968, provided early intervention within the least restrictive environment. A teacher is employed to work with an autistic child within a normal kindergarten setting and if the child is under three years of age, the teacher works within the home setting. However, it was not until 1971 that the first direct grant towards the payment of teachers' salaries was received.

The Playgroup (2-3 years) which is an aspect of the Regency Park Centre Early Intervention Program for children with physical disabilities, incorporates reverse integration, by taking into its program a small number of children without disabilities. Other programs, for example the Southern Early Intervention Centre (physical disabilities) and the Developmental Learning Program for young Down Syndrome children encourage siblings to attend so that they can also receive attention and provide appropriate models for particular group activities. When individual sessions are carried out with the children who are disabled, volunteer help can be directed towards engaging the siblings in activities.

As has been previously discussed, funding of early intervention programs is generally through several sources. For example, the Autistic Children's Association of S.A. receives 80 percent of its funding from Government sources (i.e. Department of Community Services, Schools Commission and Education Department). The remainder is obtained from public fund raising, principally through the Director of Community Relations. Public donations are made to sponsor a child, particularly in country areas.

In regard to the responses associated with the **staffing** situation, there was a focus on the multi-disciplinary team approach, although some programs were moving towards or had achieved an inter-disciplinary staffing model. This is in keeping with the recommendation in the Report of the Handicapped Programs Review (1985) to consider 'giving all disabled children below school age access to an appropriate multi-disciplinary early intervention program' (p.126). For example, the following information was obtained from the Regency Park Centre for Young Disabled, where there are 62 students with physical disabilities in the preschool section, age range 2-6 years.

Position	**Number**
Teachers	2.7
Classroom assistants	4.0
Speech Pathologists	2.7
Speech Pathologists' Assistants	2.2
Physiotherapists	2.6
Physiotherapists' Assistants	0.3
Occupational Therapists' Assistants	1.0
Psychologists	1.0
Psychologists' Assistants	0.8
Social Workers	1.0
Nurses	2.0

The pre-school also has access to a physical education teacher, peripatetic teacher, swimming instructors, and consultant medical staff. Where the early intervention program is an off-shoot of an established organisation (e.g. the Southern Early Intervention Centre), there is a similar pattern regarding professional skills although fewer in number.

Although the above two examples are from the area of physical/multiple disabilities where there is a greater history of a multi-disciplinary approach, other programs, with a traditional focus on teachers as key staff, have broadened to include other professionals; for example, a physiotherapist is a member of the professional staff in the Developmental Learning Program for young Down Syndrome children. Such programs also utilise professionals from both specialist and generic agencies.

Early intervention programs in the country experience difficulties in acquiring the specialist help that has been recommended for their clients. The Special Needs Program at the Port Augusta Childhood Services Centre employs a physiotherapist on a sessional basis (four hours per month) and they are attempting to employ an occupational therapist and a speech pathologist on a similar basis. Specialists are not attracted to the country and there are often vacancies and disruptions in services. Visits from Adelaide specialists are infrequent.

The nature of **in-service training** appears to depend largely on the level of relevant professional training of the staff who are employed to carry out the daily practical programming with the children and parents. For example, in the Anglican Child Care Services program, where there has been no specific training undertaken in terms of tertiary courses in the area of disabilities, the organisation has conducted two in-service training courses, of sixteen and twenty-five weeks duration, covering topics such as early childhood development, normalisation, behaviour modification, family therapy and systems theory. There were examinations at the end of each course and these programs were recognised by the funding body as worthwhile, with certificates being presented to successful candidates.

Where staff have relevant tertiary qualifications, the in-service training is generally on a fortnightly or monthly basis, where senior staff, professionals with specialised knowledge and visiting lecturers present information, for example, on recent developments in areas relating to the particular disability.

In examining the **philosophy, aims and objectives** of the programs, it was very apparent that the early intervention programs were working towards the philosophies and principles which are now considered to be the most desirable in guiding service delivery to people with disabilities and their families, for example, in utilising the least restrictive environment. The responding organisations focused on the following principles:

- Encouraging early identification of children with developmental disabilities so that appropriate programming can begin as soon as possible.
- Maintaining children in their own homes.
- Working with parents as co-educators.
- Integrating the child with a developmental disability into as normal a facility as possible.
- A developmental approach to learning.
- Liaising with other organisations, including generic services.
- Developing public awareness of the disability.

The majority of programs carried out their early intervention activities with children and parents on a **centre-based** model. However, home visiting was generally incorporated into the program, through a family counsellor or a member of staff who is working closely with the family. Two programs worked primarily on a **home-based** program and the early intervention program carried out by the Autistic Children's Association was both centre- and home-based, depending upon the age of the child. Programs for under 3-year-olds were carried out in the home.

The information on **practical programming** indicated a high level of commonality regarding the following:

- initial individual developmental assessments, e.g. The Portage Guide to Early Education (Bluma et al. 1970).
- utilisation of additional assessments concerning specific areas of development, e.g. gross/fine motor and language development.
- utilisation of task analysis for implementing developmental and behaviourally-oriented programs.
- individual evaluation based on data collected during individual program implementation (daily records).
- written reports which are discussed with both staff and parents. A number of programs cited a six monthly review with parents, senior staff and other staff members working directly with the family.

The Southern I.D.S.C. Childhood Services Team works in accordance with the principles incorporated in the 'Task-Centred Approach' to working with families. Specific goals are set for programs, and tasks clearly defined by both caregivers and workers together. These are recorded and reviewed continually while there is a service being provided. When services are no longer required, or appropriate, then the relationship between IDSC and the client is terminated.

Follow-up systems ranged from phone contact to home visits, regular three and six monthly checks, to the provision of life-long support for families (Autistic Children's Association of

S.A.). As most of the programs provided home support via a family counsellor, home liaison officer or social worker, the person in this role is generally the team member who conducts the follow-up with families. Liaison systems have been developed with kindergartens and schools, and where organisations do not have staff available to directly assist with the implementation of integration programs, this liaison system is utilised for follow-up in the school systems.

For families living in the outer-city areas, the **regionalisation of services** has enabled more children with disabilities to be involved in centre-based early intervention programs. In 1984, the Down Children (now Down Syndrome Association of South Australia), which has its centre-based program on the Sturt Campus (Southern Area) of the South Australian College of Advanced Education (the early intervention program has the support of the School of Special Education at this site), extended its services to families in the northern areas by establishing another program on the Salisbury Campus. Regency Park Centre for Young Disabled provides programs to assist teachers and therapists who are working with children who have physical disabilities in the country areas and the Autistic Children's Association has a country advisor. However, many families in the country, including those who are able to attend a centre-based program, still require more consistent specialist help in order to eliminate long journeys to the city.

In examining the level of **parental involvement**, the intention of all the early intervention programs was to involve all those who are directly responsible for the care and management of the child. The involvement of siblings, where appropriate, was mentioned by nearly all the respondents.

Parent education sessions are becoming a feature of a number of programs. There is a focus on behaviour management and child development, particularly language development. For some areas of disability (e.g. autism, hearing and physical disabilities), alternative systems of communication need to be taught to both parents and children.

Mothers were cited as the major participants in all the programs. However, there was evidence that a number of programs were striving to encourage the support of fathers by providing some of their activities in the evenings, in both the home and centre settings. Where it was highly desirable for both parents to attend an evening activity, efforts would be made to locate appropriate baby sitting services.

The nature of family members' involvement covered:

1. programs
2. parent support groups
3. 'parenting programs'
4. review meetings
5. committees

The corresponding rationale for this involvement was to enable parents:

1. to contribute knowledge of their child so their need and wishes could be known and incorporated into programs: to learn the skills necessary to develop, maintain and promote change. Literature support and program evidence highlight the need for consistency of approach with children who have developmental disabilities to develop, maintain and generalise skills.
2. to provide support for each other in exchange of experiences: development of group cohesion.

3. to join in sharing of information and skills: promote joint problem solving: encourage a reduction of dependence on professional assistance.
4. to affirm parents' rights: working as co-educators requires parents to be involved in decision making on priorities of the child's program.
5. to provide opportunities to influence the provision of services directly: be advocates for all children with a particular disability.

Parents are involved in the early intervention program from the time of referral unless the organisation is required to provide a diagnosis on referral which could result in recommendations to a more appropriate agency. Generally, their participation is induced by invitation from staff and other parents, open discussions regarding their value and importance in educating their child with a disability and explanations of the concept of parents as co-educators. One program discussed a formal acceptance: for example, when a child has been diagnosed as autistic, the parents are asked to write formally to accept a place for their child in the program and, in the response offering the program, the need for their involvement in their child's early intervention program is clearly outlined.

In regard to **areas of concern**, from both the professional and parent perspective, most respondents provided a list of combined concerns. These will be discussed first and then information that relates more specifically to each group will be considered.

Funding was the major area of concern for all programs and was most closely associated with lack of staff to:

1. Provide appropriate programs for an increasing number of children becoming involved in early intervention programs. With improvements in early identification of children with developmental disabilities and increased knowledge of appropriate organisations for referral, many staff members are working under considerable pressure. The writer is aware of this issue, as it was a contributing factor in the one third response rate to the questionnaire.
2. Support new initiatives, e.g. utilisation of generic services. The Playgroup Association of S.A. at present employs one special needs officer (half time) and four field liaison officers (half time) to assist the successful integration into ordinary playgroups of **all** special needs children of playgroup age in the whole of the State of South Australia.
3. Meet the needs of young children with developmental disabilities and their families in the country areas. In particular, the provision of specialist staff such as physiotherapists and speech pathologists.
4. Provide specialist services within regions. Within the city and outer city areas there is still considerable travelling time necessary for both children and families to gain access to the most appropriate early intervention program.
5. Provide more home programs and home help.
6. Provide respite care for families, in both city and country areas. This needs to be examined within the concept of normalisation principles, as increasingly families are not accepting offers to send a young child with disabilities into residential care which is removed from their local community.

In the country area (Port Augusta) funding was needed for more suitable accommodation for the program.

From a more professional perspective, areas of concern related to achieving consistent application of programs across settings, obtaining reliable, accurate feedback on programs, rectifying the lack of validated assessments on the non-verbal child in the area of language development and overcoming the difficulty of giving parents a clear idea of the prognosis for their child.

In a draft proposal for four new early intervention centres in the metropolitan area of Adelaide, two parents, writing on behalf of parents of children with intellectual disabilities, suggest that the few centres in Adelaide offering early intervention programs are unable to offer sufficient or appropriate services to all children and families who need them. They recognise that the problems associated with the present period of transition from the traditional service delivery model to the use of the generic agencies model need to be addressed.

> It is proposed therefore, that intermediate steps be taken to set up a series of early intervention centres throughout the metropolitan districts to accommodate this transition. This would involve a centre-based service with access to resources both specific to meet the need as a consequence of the disability and usual in the sense of what is used by children and families.
>
> (Robertson, & Herbert, 1985, p.2.)

In the responses to questions concerning overall **evaluation of the service**, nearly all of the respondents stated that they utilise the data from individual children's programs and these results indicate progress. Baseline data are taken on a child's initial achievement level using developmental assessments and, in one program, a video tape, with regular assessments made during the child's time in the program. Two organisations indicated that they are in the process of conducting a complete evaluation of their early intervention programs.

The information received on **future plans** addressed a number of the issues raised in areas of concern including the provision of outreach programs and home support, additional staff to conduct more in-home skills training programs and more suitable accommodation for the program (country).

Additional issues covered in relation to future plans included:

- increasing staff training in understanding family needs, management techniques, issues emanating from research into the particular disability and other special education areas.
- evaluation of parent needs and how they can be best met.
- establishing a more systematic parent network.
- establishing and maintaining close contact with relevant agencies, including local and Adelaide based, in regard to country centres. This contact was considered very important in Port Augusta, where there have been difficulties in servicing some of the Aboriginal children.

CONCLUSION

The information received on early intervention programs in South Australia highlights seven of the eight essential characteristics of effective early intervention programs identified by Pieterse (1980) and cited in the N.S.W. Early Intervention Association Report of the 1984 Membership Survey with associated Recommendations. The majority of the programs are:

- commencing as early as possible, mostly from the time of diagnosis;
- involving parents in the teaching and decision making;
- utilising a structured framework for curriculum design and teaching;

- formulating curriculum objectives around normal developmental sequences;
- setting objectives, conducting frequent assessments of progress, then utilising this information to reset objectives and evaluate teaching techniques;
- striving to ensure that early intervention curricula are sequented to the skills required in kindergarten and junior primary school in order to maintain early gains; and
- providing follow through support for children beyond the early intervention program.

The additional characteristic identified by Pieterse was in the development and implementation of the programs by an integrated inter-disciplinary staff. On this issue the responses indicated a range from multi-disciplinary, multi-disciplinary moving towards inter-disciplinary, to inter-disciplinary, with a greater focus on multi-disciplinary. Respondents also indicated an extensive network of assessment services working to support intervention programs and this feature of early intervention services in South Australia was also highlighted in the Australian Report on Early Intervention Programs (1979-80) (Watts et al., 1982).

However, there are issues of concern regarding the maintenance and development of early intervention programs in South Australia. These issues focus on the changing pattern in the system of service delivery, the movement of special services and support for persons with a disability into a local integrated and co-ordinated service system, and funding concerns.

The following questions require immediate attention.

1. Who is to take responsibility for:
    a. funding the change from specialist to generic services, and
    b. providing a guarantee of a forward commitment of funds?
2. During this transition period, where there is increasing involvement of government and voluntary organisations, to whom are staff ultimately accountable?
3. Who will take the responsibility of ensuring that all children with a disability and their families receive the most appropriate early intervention services both now and in the future?
4. How is this period of transition to be co-ordinated at both a formal and informal level?

While many of the developments in South Australia are exciting in regard to the practical implementation of the principles of normalisation, there needs to be careful planning to ensure that early intervention services are comprehensive and coordinated.

To assist in this planning, the author's major recommendation is for a State Early Intervention Association. A number of professionals working in the area have been discussing this need at an informal level and very recently the matter was discussed at a meeting of the South Australian Institute on Developmental Disabilities Inc., which is an independent co-ordinating body, representing the major agencies servicing people with disabilities in South Australia. This would also assist communication at the National level, as the author is aware of two State associations, the New South Wales Early Intervention Association (1983) and the Victorian Early Intervention Association (1985).

The author also recommends the employment of a person on a full-time basis for a specific time period to carry out comprehensive research on early intervention programs in South Australia, including substantial time for direct contact with the programs. A South Australian Early Intervention Association would be the most appropriate vehicle for the promotion of such a research project, and such an association was formed at a public meeting on September 7, 1986.

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Chapter 6

EARLY INTERVENTION IN WESTERN AUSTRALIA

Errol Cocks

INTRODUCTION

This is primarily an account of the development of early intervention services provided by the Authority for Intellectually Handicapped Persons (AIH) in Perth, Western Australia. Brief information is included on the services provided by three other agencies, the Association for Autistic Children in W.A. (Inc.), the Spastic Welfare Association (Inc.) and the Princess Margaret Hospital for Children. Although this is not an exhaustive coverage, these services account for the great majority of early intervention services for children with developmental disabilities in Western Australia. Three programs not described here are the Parents as Educational Partners program at Murdoch University (described in Chapter 15), a small early intervention program in the process of development in the Psychology Department of the W.A. Institute of Technology and the services provided by the Child Development Centre of the W.A. Health Department.

W.A. AUTHORITY FOR INTELLECTUALLY HANDICAPPED PERSONS

ORGANISATIONAL HISTORY

AIH plays a major role in the provision of early intervention services for children with intellectual disability in the Perth metropolitan area. It was established by an Act of Parliament in January 1986, and is the only autonomous state government organisation in Australia with responsibilities for the provision and development of comprehensive services for people with intellectual disability. AIH's origins were in the creation of the Mental Deficiency Division in 1964 as a structure within the W.A. Mental Health Services.

The Division took responsibility for Irrabeena, an assessment and diagnostic centre, developed a range of direct services and adopted the role of coordinating services provided by other agencies, notably the SLCG (Inc.) (An association for developmental disability in W.A.). The Division made a significant decision to follow the developmental model and in 1964, created a new group of specially trained direct service workers, now called social trainers.

THE DEVELOPMENT OF EARLY INTERVENTION SERVICES

Prior to 1978, services for preschool children with intellectual disabilities provided by AIH included assessment and diagnosis, with referrals accepted from any source. Traditional therapy programs were provided within two occupational therapy and two physiotherapy day units and a small number of preschoolers were able to attend a special kindergarten called Elwyn Morey (Cocks, 1979). The availability of home-based support was minimal.

In 1976, a purposeful attempt began to develop a system of comprehensive early intervention services in the Perth metropolitan area for the 240 preschool children at that time registered with AIH. A pilot early intervention program was implemented by a milti-disciplinary team to 16 children under three years of age. The program focused on home-based services, high levels of parent involvement and systematic intervention through structured programs based on a criterion-referenced instrument developed for the program, the Irrabeena Early Intervention Scales. The pilot program provided considerable impetus for change within the organisation and in 1978, a comprehensive service was introduced by the allocation of a multi-disciplinary team of staff to each of four resource centres within geographical regions.

Teams were given an explicit, written brief to develop services according to five principles:

1. the maximisation of parent consultation and involvement;
2. emphasis on home-based intervention for younger preschoolers;
3. emphasis on a broad, educational orientation in programs;
4. emphasis on parent skill development;
5. provision of support to generic agencies.

An evaluation system was built into the service to measure elements of both process and outcome. Process evaluation involved the gathering of 'service utilisation' data for each of the families which measured the extent to which services were provided and utilised according to the five stated principles. Data from the first nine months of service delivery confirmed a high degree of adherence to the principles (Cocks, 1979).

Outcome evaluation involved measuring the developmental gains of a group of 49 children aged between 12 and 48 months who received services between June and December, 1979. On norm-referenced measures, the children gained at rates varying from less than 50% to well over 100% of 'expected' or 'normal' rates of development. On criterion-referenced measures, an average of 2.58 skills per week were gained, with considerable differences occurring between age groups and skill areas (Cocks, 1982). Gilomen (1983) also describes the evaluation system.

Two specific factors have influenced the continued development of early intervention services within AIH. First, although resources have remained virtually static, demands for services have grown. In 1978, 240 preshcool children with intellectual disabilities were receiving services and, in June 1986, this number had grown to 331. Second, in 1984, AIH regionalised all services. Prior to this event, preschool services had a clear identity within the organisational structure under a senior administrator with overall responsibility for services. Under the current structure, services are subsumed under one country and four metropolitan regional directors who are responsible for all AIH services within their respective region. Inevitably, this has reduced focus on the area.

CURRENT SERVICES

Current AIH early intervention services are comprehensive in the provision of:

- assessment and diagnosis;
- individual intervention programs for each child and family;

- both home and centre-based programs;
- support for children in generic services;
- family counselling and support;
- consultative services to other agencies.

As the overall system is complex, this account will identify and describe only some of the more important characteristics of the system.

Service-users

In June 1986, a total of 331 children born from 1980 to 1986 were receiving services within four metropolitan regions. Table 1 describes the age distribution of those children by region.

Table 1

Age Distribution of AIH Metropolitan Preschoolers — June 1986

	YEAR OF BIRTH							
Region	*1980*	*1981*	*1982*	*1983*	*1984*	*1985*	*1986*	*Total*
Northern	4	24	20	20	10	6	4	88
South Eastern	14	22	14	17	12	7	3	89
Eastern	10	12	19	21	18	6	1	87
South Western	7	14	15	18	6	7	0	67
	35	72	68	76	46	26	8	331

Policy Development

Eligibility for AIH services is determined by the definition of intellectual disability of the American Association on Mental Deficiency (Grossman, 1977). For young children in particular, reliance on normative assessment has well-known inadequacies. In 1982, a formal policy was adopted to provide services to children under four years who were considered to be 'at risk' or 'vulnerable' although their level of functioning may not indicate intellectual disability.

With the large size of the state, provision of services generally to people with disabilities living in country areas is acknowledged as inadequate. Currently, AIH provides services to over 850 persons of all ages in 11 country areas throughout the state. Only one centre, Bunbury, with over 280 service users, has a team located in the area. Other centres receive two or three visits each year from a Perth-based, multidisciplinary team of AIH staff which works through and supports local agencies. Within this context, early intervention services in rural areas of W.A. are very limited.

Developmental Assessment

The principal method of developmental assessment used by AIH teams is the Irrabeena Developmental Assessment which was developed from the earlier Irrabeena Early Intervention Scales and introduced in 1982. The Irrabeena Developmental Assessment is a detailed, criterion-referenced scale assessing fine and gross motor development, receptive and expressive language, cognitive development, self-help skills, socialisation and play. The scales are age-referenced.

Teams have adopted a number of policies regarding assessment:

1. assessment should be related to program development;
2. assessment using the Irrabeena Developmental Assessment should formally commence at six months of age;
3. all children should be assessed on the Assessment at least once every two years if parents are agreeable and the child continues to receive AIH services.

Team Agreement Process

The first team agreement process was introduced within each of the preschool regional teams in 1981. It was aimed at the development of a systematic approach to assessment and programming which would allow for greater parental input into programs. The process was explicit and included considerable documentation to facilitate accountability.

The current process was introduced following a review, in June 1983. Within the formal process, the Service Coordinator plays a central role. This person, usually the most appropriate member of the team in terms of the family's needs, is allocated to the family following referral and has specific responsibilities to coordinate and maintain suitable services.

The steps in the team agreement process include:

1. **Initial Family Contact.** This occurs within two weeks of referral acceptance and confirms a schedule of assessment over a two month period;
2. **Needs Establishment.** Needs are established by social, medical and developmental assessment, by parental definition of needs and from information obtained from other agencies if appropriate;
3. **Reports.** These are completed and coordinated by the Service Coordinator;
4. **Home Visit.** This involves discussion with the family to agree on priorities for the intervention;
5. **Team Agreement Meeting.** This meeting includes the parents if possible and establishes long and short term aims, the nature, location and frequency of intervention and who is responsible for providing services;
6. **Implementation.** The planned intervention program is then implemented;
7. **Outcome Phase.** Outcomes are documented according to the written team agreement and changed family needs are reassessed in preparation for the process to begin again;

The basic mechanism of the team agreement process is the contract between members of the team, the family and possibly other agencies. Each step in the process requires specific documentation known as 'File Criteria'. The extent to which the process is utilised may then be evaluated by audits of the files of service users. In September 1983, for example, an audit of 91 files indicated a high level of compliance with the process.

Program Data

Since its inception, this program has emphasised a high level of accountability through ongoing collection of relevant data. This includes a computerised database of service users containing a range of sociodemographic and diagnostic information on every AIH client.

Program process data have been collected and computerised since 1978. The information is collated monthly for each preschool child and within each region. The data provide an effective means of describing and monitoring certain aspects of the service provision system. For example:

- It constitutes a method of 'tracking' so that service users are not 'lost'.
- It monitors the extent of services-user contact. For example, between 1978 and 1985, average monthly client contact from regional teams was maintained at between 63% and 86% of total service-user numbers.
- The nature of service-user contact in each region according to whether contacts occurred within a home-based or centre-based program can be monitored. In 1985 in one region, for example, 36% of contacts occurred within centre-based and 50% within home-based programs.
- Adherence to broad policy emphases can be monitored. For example, between 1978 and 1985, for all four regions, 45.9% of all client contacts occurred in the child's home. This reflects a policy emphasis on home-based intervention.

There has been only limited attention given to measures of program outcome although considerable data are available from developmental assessments of individual children. Two small outcome studies have been carried out, the first in 1979 and referred to above (Cocks, 1982). The second, in 1983, was not published. It involved a small sample of eight children aged from 19 to 53 months of age who were assessed on the Irrabeena Developmental Assessment with 4.5 to 7.7 months between assessments. 'Developmental rates' were determined for each child and consisted of the ratio of months of gain in Irrabeena Developmental Assessment score and months elapsing between assessments. The average rate of development for the eight children was 71.4% with a range of 45% to 122%.

A number of other studies have been carried out since the program's initiation but, unfortunately, none have been published. These included a study of the time usage of social trainers in 1980. Social trainers provide the major direct service function. In 1984, a parent survey was conducted to elicit feedback regarding programs and service delivery. This culminated in a statement of 'Principles of Programming for Preschool Children' covering processes of goal selection, program writing, implementation and evaluation.

Documentation

AIH publishes a Parent Handbook for parents of preschool children who use services. The handbook provides an overview of the services in the preschool area and lists resources available for families. A check list is included which specifies a number of concerns which parents may have such as the roles of various team members, assessment, respite services and preschool and school provision for children with intellectual disabilities. The check list may be used as a guide for parents in seeking information from team members. A Staff Resource Manual is available containing information corresponding to the areas in the parent check list.

Future Development

The development of this comprehensive early intervention service, which is nearly a decade old, provides interesting insights within the context of organisational change. The service has a number of valuable characteristics. It is primarily a service-oriented program located within a broad, mainstream service for people with intellectual disabilities. The program thus is easily accessible. Within this context, it developed from a set of well-explicated, rational and systematic principles and maintained a commitment to data-based accountability. Introduction of the program resulted in structural, organisational and programmatic changes. This was followed by a period of consolidation and further sophistication of program content and procedure. Some momentum and focus was lost in 1984 when AIH regionalised its entire services.

Recent events indicate a renewed interest in the program area and the possibility of further service development. Following a Preschool Forum in December 1985 which involved input from each region, an Early Childhood Interest Group was established. This Group, through the AIH Research and Evaluation Unit, has initiated a major review of presechool services, which, it is hoped, will be published.

Two regional teams also have developed projects focusing on more effective home-based intervention. One of these has been documented (Roche, 1986).

THE ASSOCIATION FOR AUTISTIC CHILDREN IN W.A. (INC.)

The Association, a parent organisation, initiated the Community Integration Program in February, 1981. As a matter of central policy, the Association does not have centre-based programs but rather provides integration assistants assigned, for varying amounts of time, to children with autism to support them in integrated educational placements.

In 1986, the Association provides services for nine children with autism who are between the ages of two and five years in an identified early intervention program. In addition to integration assistants, staff resources include an educational psychologist and speech therapist.

The program focuses on parent support and child development. Parent support is provided both individually and in groups. Three phases have been developed. The first phase provides parent guidance in areas that include dealing with family reactions to the diagnosis, future expectations, the effect of autism on child development, particularly in cognitive and language areas, behaviour management, teaching techniques and the availability and accessibility of various community services. Phase Two introduces weekly program goals for each child and support to implement programs through integration assistants. Phase Three provides consultation depending upon family wishes and needs. Families may also use respite care services provided by the Association for short periods of time.

As the child's educational needs become too complex for the parents to meet at home without assistance, integration assistants are provided in one-to-one individual sessions in the home or other appropriate settings. Children may attend play groups and preschools with the support of integration assistants. Programs focus on attentional skills, cognitive development and the teaching of functional language.

The objective of the Association's early intervention program is to enable all children to attend their local primary schools with the suport of an integration assistant to the extent required.

THE SPASTIC WELFARE ASSOCIATION OF W.A. INC.

The Spastic Welfare Association of W.A. Inc. has been providing day programs for infants with cerebral palsy and their families from about 1977. Since 1980, a total of 110 children with cerebral palsy have been admitted to the Association's early intervention programs. Referrals are accepted from any source.

Following initial assessment, children attend centre-based programs coordinated by a teacher with specialist preschool training. Physiotherapy and social work support is provided to the program, with occupational therapy and speech therapy available as required. The primary objective is to provide early treatment to promote the maximum independence of the child which will enable integration into community educational options wherever possible.

PRINCESS MARGARET HOSPITAL FOR CHILDREN

The Department of Developmental Paediatrics and Rehabilitative Medicine within the Princess Margaret Hospital for Children provides diagnostic, consultative and management services for children with developmental disabilities. The Department provides various clinics including:

- access to a multidisciplinary team through the developmental paediatrics clinic;
- an early intervention clinic, specifically for children under two years, providing counselling and management plans;
- a seating and posture clinic.

The Department provides routine follow up of neonates considered 'at risk' and group intervention for parents of children with developmental delay. The domiciliary aid program provides advice and help on any modifications required to support children with physical disabilities living at home. The Hospital also provides day care facilities that cater for children with disabilities. In addition,the developmental paediatrician in charge of the Department serves as a consultant for various services outside the Hospital, including those concerned with physical disabilities, cerebral palsy and autism.

There are close links between this service and the Child Development Centre of the W.A. Health Department, which provides a range of services to children with disabilities, particularly in the area of ongoing assessment.

CONCLUSIONS

There are a number of challenges ahead for the development of early intervention serviced in Western Australia. For example, early intervention is well established within service providing agencies. However, there would be considerable benefit if links could be formed between these agencies and external sources of evaluation, possibly within tertiary institutions. The evaluation of program outcomes in terms of developmental gains and the often-stated goal of achieving greater educational integration require examination.

For many years, early intervention programs have emphasised the involvement of parents in setting objectives for their own children and in program implementation. Involvement of parents in policy development and service planning has not received similar attention in Australia. The challenge is to develop mechanisms to facilitate parent involvement in these wider issues. Such involvement may well serve to shift program emphasis from a focus on the developmental gains of the child with a disability towards the ecology of the whole family's needs. This may lead to an acknowledgement of the importance of meeting basic family needs such as for respite services, contact with other parents, home-help and support for other family members, particularly siblings, and to an appropriate allocation of resources to those areas.

New forms of service delivery need to be implemented to meet the needs of isolated communities in the State for early intervention services. Service models and technologies already exist. This forms part of a broader challenge to deal with increasing demand for services and the probability of, at best, static, but possibly declining, service resources. It is intriguing that whilst formal service systems point to resource shortages as reasons for insufficient services, some individual families mobilise large numbers of friends and neighbours to carry out hours of patterning exercises daily for their children over many months. Careful strategies need to be developed to mobilise this form of support for families and also to utilise to a much greater extent, generic community resources. Notably in Western Australia, child care services are becoming increasingly available to young children with disabilities as a matter of conscious policy and this can only be seen as a positive trend.

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Chapter 7

EARLY INTERVENTION IN TASMANIA

Alison Jacob

Historical Perspective

Early intervention services for developmentally disabled children in Tasmania have developed rapidly in the past few years. As recently as 1979-1980 there were few services and little support for early intervention programs. The Schonell survey (Watts, et al. 1982) reported:

> Overall, early intervention services in this state presented as being fragmented. They were divided between health and education authorities, and were mainly add-on programs to existing services. There was considerable evidence of lack of communication between programs and information about programs. (p.70)

Since that time, several significant Tasmanian reports have supported the concept of early intervention. The Education Department's 1983 **Review of Special Education**, stated:

> The Education Department should accept responsibility for early education intervention, and should develop and communicate a policy on this matter. (8.7)

A Government working party on **Multi-disciplinary Assessment, Diagnosis and Early Intervention** was appointed in 1982 to examine present services and make recommendations. A further report into the needs of intellectually disabled people in Tasmania (Foster, 1984) recommended that 'High priority in funding be given to early intervention programs' (p.273). During this period early intervention programs have expanded rapidly in line with educational responsibility. Being a small state there have not been the problems of multiple programs and agency involvement which plague larger states. It has also been possible for the Education Department to assume a co-ordination role.

In 1982 the Education Department appointed a teacher to each of the three educational regions to assist in delivering early intervention services. Further funding was provided by the Education Department in subsequent years. At the same time, the involvement of Schools Commission Special Education programs in early intervention facilitated program development. In 1985, the Education Act was amended to give official credence to Education Department involvement.

Assessment and Referral Systems

The Child Health Service provides early examinations for 98% of infants in Tasmania (Foster, 1984). Children considered to be at risk may be referred from birth onwards to an Assessment Centre in each region. These Centres are staffed jointly by the Health and Education Departments and offer multidisciplinary assessment, therapy, and support services for young developmentally delayed children. A separate Health Department Multidisciplinary Centre, the Douglas Parker Rehabilitation Centre, offers therapy and support services to some developmentally disabled children, although the concentration is on children with physical or multiple disabilities.

Children considered to be significantly at risk of developmental delay may be referred to early intervention programs from any source, including parents, doctors and community agencies. Referrals in each of the three regions are co-ordinated by interagency committees representative of agencies involved in offering early intervention programs, which make recommendations on the most suitable service for a particular child. The Education Department assumes the administrative role for the committees, which attempt to ensure a comprehensive and unified early intervention service.

Educational Programs

The Education Department considers parental preferences when offering home and centre based programs in all regions. The emphasis in these programs is on parents and families, and the teachers work through the parents, whenever possible. The programs are broadly based and include three components:

(a) reliable, updated information to the family;

(b) counselling to reduce tensions and problems which may arise with the presence of a developmentally delayed child; and

(c) a structured educational program designed to meet the needs of the child.

As an example, in the Southern region two major programs are offered. The first is based at a 'Parent-Centre' which is centrally located. The second is based at a kindergarten room at Herdsman's Cove, an outlying suburb with a disproportionately high level of low socio-economic groups. In addition to these services, the Education Department has special kindergartens for children who need an intensive program (e.g. Warrawee and Rothesay). Early entry to regular kindergartens is also offered if there are particular reasons and various schools have also set up early intervention programs using school-based resources, to cater for a small number of children. This includes some independent centres such as the Lady Gowrie Centre in Hobart.

Special schools and units in rural areas frequently offer a limited early intervention service for children within that area; examples are Huonville and Oatlands. As noted earlier, programs are also provided in a 'day training centre' in each region. Each centre offers a centre-based program which contains teacher and therapist input, but is provided by social trainers or child carers. The centres in the north (Quindalup) and south (Elonera) are currently administrated by the Mental Health Services Commission, while the Centre in the north-west is administrated by the Retarded Citizens Welfare Association. Negotiations are presently underway for the Education Department to assume responsibility for all three centres. (A list of programs currently available may be obtained from the author).

Client Group

Tasmania's population is relatively small, with approximately 6,500 births per year. The number of developmentally delayed children is correspondingly small, and the state is able to cater for most children referred for programs. As an example, the primary educational program in the southern region caters for 43 children; 11 Down Syndrome, 7 severely developmentally delayed, 25 developmentally delayed. Several of these children have delays contributed to by adverse socio-economic circumstances.

Throughout the state, approximately 160 developmentally delayed children are receiving an early educational instruction service.

Particular State Characteristics:

Several factors have shaped the development of early intervention service in Tasmania. The most obvious are:

(1) The small client group;
(2) The small number of agencies involved;
(3) The assumption of responsibility by the Education Department;
(4) The amendments to the Education Act;
(5) The relatively late advent of programs which could be based on model programs demonstrated elsewhere, and available research evidence.

The most positive results of these factors are:

(1) The co-ordination of services within each region into a unified, cohesive service.
(2) The relative avoidance of duplication of programs;
(3) The availability of programs for most referred children;
(4) The expansion of services into areas of low socio-economic status, where there is a high proportion of developmentally-delayed children.

Particular negative consequences are also identifiable. They are:

(1) The lack of variety in programs offered in terms of philosophical approach;
(2) The small number of professionals working in the area leading to some professional isolation;
(3) The problem of providing services in rural areas;
(4) The problem of establishing credibility in the early years of programs.
(5) The difficulty of professional development for small numbers of staff.

Initiatives

Tasmania has been in a position to cater for a wider range of developmentally disabled children than most other states, since programs have catered for children whose developmental integrity is threatened, because of adverse environmental and socio-economic conditions, to a substantial degree. The philosophy of programs has accepted the premise that environmental risk is a legitimate reason for intervention and that developmental disability is often a result of a matrix of factors which include both the characteristics of the child and the characteristics of the environment in which he or she is raised. Research currently being undertaken in the state is attempting to further isolate environmental factors which have predictive value for children who are 'at risk'.

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Chapter 8

EARLY INTERVENTION IN NORTHERN TERRITORY

June Rouse

1. INTRODUCTION

The Northern Territory, with a population of 145 000, covers a land area of 1 348 000 square kilometres. The climate varies from monsoonal in the northern coastal regions, which have an annual rainfall of 1500mm, to desert conditions in the centre where the annual rainfall can be less than 200mm. The vastness of the Northern Territory, combined with the fact that the majority of the population is concentrated in five major centres, with the remainder scattered widely, has resulted in a unique educational service for children. Living and teaching conditions vary greatly, reflecting the inevitably wide variation in schools and locations. The range of educational services for school-aged children includes one-teacher units in isolated areas, large and small Aboriginal schools, area schools, schools of the air, a secondary correspondence school, large metropolitan primary and secondary schools and junior and senior secondary colleges. Likewise, the range of special educational services available varies widely according to location.

There are five main urban centres in the region, each with a characteristic residential pattern:

> **Darwin** is the capital of the Northern Territory with a population of 65 000. The community is multi-cultural with over fifty ethnic groups represented. Most families have come either from southern cities or other countries, and therefore do not have an extended family living close by. The Dry Season is also known as the 'Granny Season' as it brings an influx of elderly people visiting their families. Likewise, at Christmas time, many families leave town, firstly to escape part of the Wet Season, and secondly to spend Christmas with their families in southern cities.
>
> **Alice Springs** is approximately 1600 kilometres south of Darwin and has a population of 21 000. The community is predominantly European with a substantial Aboriginal population in the surrounding district. There are approximately 1000 personnel employed at the Pine Gap Space Research Station just out of Alice Springs. The town is in semi-arid region, where temperatures range from −4 to 45 degrees centigrade.
>
> **Katherine** is situated 350 kilometres south of Darwin and has a tropical, monsoonal climate. The population is predominantly European, with a small number of Aborigines living in the town or in fringe camps. There is currently an influx of service personnel because of the expansion of the Tindal airbase.
>
> **Tennant Creek** is 900 kilometres south of Darwin and its population of 3200 is also mainly of European extraction with a small number of Aborigines.
>
> **Nhulunbuy** is situated on the Gove Peninsula in North-East Arnhem Land. The town was established in 1969 to service the Nabalco bauxite mining venture and has a current

population of 4000, mainly mining personnel and related service providers.

In addition to these five main centres of population, there are a number of outstations, some more isolated than others.

2. PROBLEMS IN SERVICE DELIVERY IN THE NORTHERN TERRITORY

Apart from the perennial problem of too few qualified staff, there are a number of specific problems in providing services to families with disabled children, arising from the unique characteristics of the Northern Territory community and its geography. For example, the transient nature of the population, the diversity of cultural groups represented and the lack of extended family support for most of the non-Aboriginal families all present special problems for professionals working with these families.

In addition, there are obvious logistical problems in providing a service to a scattered population in an area where travel is often rendered difficult or impossible by the climate. As some locations provide no overnight accommodation, camping gear is sometimes necessary, as well as insect repellant, torches and strong walking shoes! In addition, permits are required to enter Aboriginal settlements. When travelling long distances by four-wheel drive, a two-way radio and plenty of water are essential in case of breakdowns. In the build-up to the wet season, it sometimes happens that a dry road used to reach a destination is rendered impassable on the return trip by a heavy storm. The more isolated outstations are normally accessible only by light plane, but even airstrips may be closed following prolonged rain. Communication in such circumstances is reduced to radio contact.

Providing services to isolated Aboriginal communities presents special difficulties associated with differences in tribal culture and lifestyles. There is no common Aboriginal language, and one may find as many as eight languages spoken in one settlement, such as at Maningrida. While some English is spoken in all settlements, it is frequently quite unknown to children in the 0-5 age range, and often only begins to assume importance when formal schooling begins. The range of educational toys and equipment that may be seen in European early intervention centres and homes are generally not only unavailable but also quite irrelevant to the Aboriginal child. Thus early intervention advisers must find alternatives that are matched to the family's local environment. Similarly, appropriate alternatives must be found for the usual range of aids, rests and supports recommended by therapists for the exercise and physical development of a disabled child.

In summary, professionals providing any specialist service to isolated Aboriginal families must be aware of and sensitive to the child's environment and program accordingly to meet the child's needs.

3. EARLY INTERVENTION SERVICES

Early intervention provision throughout the Northern Territory is still in its infancy. A variety of services is provided to disabled children aged 0-6 years by the Departments of Education and Health and by a number of voluntary agencies, such as the Northern Territory Spastics Association. Each department and agency has developed its own policy with respect to service implementation. As in other states there is at present no formal overall coordination of policies towards these early childhood services. Informally, however, there is quite a high degree of cooperation and coordination at the service delivery level, reflecting both the nature of the community in the Northern Territory and the small absolute number of people involved.

Services Provided by the Northern Territory Department of Education

The Northern Territory Department of Education now employs a full-time Officer for Early Intervention who is responsible for the coordination of the state-wide provision of educational services to disabled children aged 0-6 years. In addition, the Department employs two education officers with responsibility for areas of specific disability, one for Visual Impairment and one for Hearing Impairment. As well as their work with school-aged children, both these officers assist the Officer for Early Intervention in working with children below school age. All three education officers travel extensively throughout the Territory, providing support to both home-and centre-based programs as needed.

Centre-based early special education services are provided by the Department in Darwin, Alice Springs, Tennant Creek and Nhulunbuy. Several of the centres have full-time teachers, while others are serviced by part-time teachers. For more isolated families and communities, early special education services are provided on request, usually taking the form of advisory visits from professionals appropriate to the particular needs of the disabled child.

4. EARLY INTERVENTION IN ISOLATED AREAS

There is no doubt that the level of service that can be provided in an urban area such as Darwin cannot be duplicated in either a small town such as Tennant Creek, or in an isolated community such as Murganella. In addition, daily commitments within the major centre, together with restricted funding, do not allow for specialist visiting on a regular timetable basis. Thus, in this respect, all people who live outside the main centres of population and require specialist services are disadvantaged.

Some attempts to minimise the effects of isolation include the utilisation of special travel funds, such as the 'Isolated Children's Allowance', to enable children to be brought into Darwin for assessment and programming. Accommodation is provided on a limited basis by the Harry Giese Centre.

Radio and telephone contact is very important, and has been utilised over a number of years, but a more recent medium being developed to assist parents with ongoing home programming is the video cassette, on which programs may be recorded in Darwin centres and sent out to parents for their use. A reverse utilisation of this resource occurs when the Education Officer for Early Intervention (EOEI) records the situation in the isolated home and, with parental permission, replays this to involved Departmental personnel on return to Darwin. This enables more effective advice to be given to parents by personnel such as therapists, especially when they are unable to visit immediately.

5. THE ROLE OF THE EDUCATION OFFICER FOR EARLY INTERVENTION (EOEI)

In all instances of early special education provision, the Education Officer for Early Intervention is the initial referral officer. The referral system is extremely flexible to allow children to be referred by parents, doctors, care-givers, therapists, student services, colleagues and teachers.

The EOEI probably has the widest ranging brief in special education in the Northern Territory, with the exception of the Superintendent of Student Services, to whom he/she is directly responsible. Having a responsibility within the age range 0-6 years, the EOEI often makes the first 'hands on' contact with the child and family in the home. From then on, the parents may regard this officer as their principal adviser and counsellor, because he/she maintains regular contact with them until the child enters full time primary education. Over a period of three years or more, the EOEI coordinates education programs for the child, counsels parents on Departmental procedures, on home management strategies, arranges referrals to other personnel or agencies as appropriate, assists the parents in conferencing and prepares preschool teachers for the entry of the child into their classes.

As the child approaches the age of six years, the EOEI arranges for the transition of the child from the early intervention program into the primary school program. This involves close liaison with Student Services colleagues and schools, the introduction of the parents to this wider educational service provision and the officers concerned, and detailed attention to the ongoing programming needs of the child.

As with intervention for hearing and visual impairment, the service to children with other disabilities in isolated areas, is provided by the EOEI. On such occasions, the officer will spend three to seven days away from the Darwin base and may be accommodated with the family, stay in designated accommodation on the settlement or in a motel (Alice, Katherine, Nhulunbuy).

6. EARLY INTERVENTION SERVICES FOR SPECIFIC DISABILITY GROUPS

(i) Services for the Developmentally and Physically Disabled

Initial intervention for children with a wide range of physical and intellectual disabilities is provided in Darwin at the Northern Territory Spastics Association Centre, known as the Harry Giese Centre. As the service provided here is transdisciplinary, children are often referred soon after birth and, in conjunction with therapy, receive an educational input as soon as possible.

The team at the Harry Giese Centre includes a part-time paediatrician, psychologist, social worker and full-time speech, occupational and physiotherapists and aides. The Department of Education provides the services of three full-time special education teachers, a guidance officer and the support of the Education Officer for Early Intervention. These staff are administratively responsible to the Department of Education. In addition, Commonwealth Schools Commission Early Special Education funds are used to employ a part-time instructor whose role is to assist children from the Centre to integrate into their local preschool.

The babies/toddlers program is run by therapists while from the ages of 2 to 2½ years, teachers are involved also. Children are formally placed in the educational program following a case conference which involves parents in the decision-making process. The Officer for

Early Intervention helps prepare the parents for this meeting with professionals. A decision to place a child in the special education program is generally based on the judgment that the child requires special education or special education plus extensive or intensive therapy. Subsequent case conferences review the child's placement, progress and future options. From the beginning of 1987, parents are involved in all case conferences, along with the relevant professionals.

(ii) Early Intervention for the Hearing Impaired

Programs for hearing impaired children are available in Darwin. Families are eligible to participate in the program as soon as the children are identified through the National Acoustics Laboratory (NAL), which maintains a close liaison with the Department of Education. The programs are 'home-based' but do involve some visits to a central facility. Financial assistance is available to parents who transport their children to and from this centre.

Early intervention programs for hearing impaired children in the 0-3 year age group have been provided by the Department of Education since 1979. At age 3 years, the children are eligible for entry into preschool. The children may enter either a special preschool for hearing impaired and normal hearing children or attend their local preschool with support from specialist teachers. Where a child with hearing impairment also has other disabilities, the Education Officer for Early Intervention assists the Officer for Hearing Impairment and acts as a program coordinator.

The Education Officer for Hearing Impairment provides an advisory service to children in isolated communities within the Northern Territory, north of Elliot. Services in Alice Springs and the southern region are yet to be developed to the level of those in Darwin.

(iii) Early Intervention for the Visually Impaired

A coordinated intervention service exists in Darwin, involving the Department of Education, the hospital ophthalmologist, the low vision optometerist and the Royal Guide Dogs for the Blind Association. Initially, education programs are 'home-based'. The Education Officer for the Visually Impaired visits the child in the home and assesses the educational implications of the diagnosed sight condition. Often, this visit is made in conjunction with the Officer for Early Intervention, who is able to assist with family counselling and who will become more involved if other disabilities are diagnosed. However, if the disability is specifically visual, the Officer for Visual Impairment will assume the full responsibility for educational programming. When the situation requires that the child be provided with a program which cannot be implemented within the home setting, arrangements are made for the child to come to Darwin.

In addition to these officers, the Department employs an Itinerant Teacher of the Visually Impaired to assist, on a regular basis, in the home, the creche and the neighbourhood preschool.

There exists the provision for early entry into the local preschool for visually impaired children and specialist teachers are employed in Darwin. Special education teachers are employed in other centres. The Officer for the Visually Impaired has a territory-wide responsibility and may travel to other urban centres or isolated areas on request. Telephone links are maintained with families once programs have been initiated.

(iv) Services for Children with Communication Disorders

There is a special centrally located preschool in Darwin catering for children with communication disorders. The maximum number of children per session is five, and may also include children who are hearing impaired. Children may enter, if appropriate, as late as five years of age. The centre is located on the campus of a regular preschool. Reverse integration of normal five year olds is planned so as to provide normal models of language, while four year olds from the special facility are given opportunities to integrate into the regular preschool.

7. CONCLUSION

In view of the relative recency of the introduction of special education services into the Northern Territory, the rapid progress achieved in developing special educational services for very young children with disabilities is noteworthy. Despite the lack of formal coordination of services, and the multitude of unique problems in providing services in the Northern Territory, a very comprehensive network of early intervention services is available, particularly in the Darwin area. The key role in the coordination and provision of these services to families in the Northern Territory with young disabled children is played by the Education Officer for Early Intervention. For more isolated families, both of Aboriginal and European origins, living on mission stations, in Aboriginal settlements and other remote outposts, his/her role is vital, both in providing a direct educational service, and in establishing and maintaining contact between their disabled child and the necessary specialist services. The following case studies illustrate the range of services provided by the EOEI as well as some of the unique features of service provision in the Northern Territory.

CASE STUDIES — NORTHERN TERRITORY

1. Home-based Program for a Severely Retarded Boy Living in an Isolated Community

The child's family is one of two European families living a little inland from the coast in a small, largely Aboriginal community. There is no school, so children receive School of the Air. The nearest health facilities are a 2½ hour boat journey away on Croker Island. The main form of communication with the outside world is by radio. A light plane visits once weekly (twice on pay week) on a Conservation Commission charter flight, and the Department of Education can use this service free of charge. Road access is only possible in the Dry Season — a six-hour drive, half of that on a bush dirt road.

The child had been assessed at the Harry Giese Centre every six months and established on a home-based program while the family was living in Darwin. The home-based program has been continued in the isolated setting, with the mother working with her son three hours daily.

As Early Intervention Officer, I visited the home and stayed with the family, in order to observe first hand the home environment and family life style and thus be in a position to make more appropriate programming suggestions. While there, I had parental permission to film the mother working with her son.

As a result of this visit and the video, a number of things were achieved.

1) I was able to help organise assistance for the mother from someone in the com-

munity, thus enabling her to spend more time with her other non-disabled child.

2) After seeing the video film, the mother became aware of the other child's need for more attention and involvement from her mother — the child was clearly exhibiting a number of attention seeking behaviours. She also could see ways of modifying her son's program.
3) On the family's next visit to the Harry Giese Centre, therapists were able to be more realistic with their programming suggestions.

2. Premature Aboriginal Baby

This child, who lives in the Numbuluwa Aboriginal settlement, was seen by therapists who then arranged for the family to visit the Harry Giese Centre. A case conference was arranged, including myself as Early Intervention Officer and the Education Officer for the Visually Impaired, as the child was severely visually impaired and appeared, in that setting, to have other developmental delays. I subsequently visited the baby in the settlement and found that she was functioning normally as compared with the other Aboriginal babies of a similar age, particularly in motor areas. A program was established for the child that was appropriate to her home environment, using lay people in the community (health sister and local school personnel). This case study highlights the great importance of professionals assessing a child in the context of his or her own culture.

3. Preschool-based Program for a 3½ Year Old Down Syndrome Child

The child's family arrived in Darwin from Townsville. From all data available, it was clear that the child was functioning within the normal range with the exception of her expressive language. The most appropriate and least restrictive environment at this time was therefore considered to be her local preschool. The child now has the support of a part-time instructor for an hour each preschool session so that she can receive intensive tuition. Progress is reviewed regularly by the Harry Giese Centre team. The child's parents are involved in program planning and follow through in the home environment. As EOEI, I coordinate the total program.

PART 2

SERVICES FOR CHILDREN WITH DISABILITIES AND MODEL PROGRAMS

Chapter 9

INTRODUCTION

Moira Pieterse

Models of service providing early intervention for developmentally disabled children are outlined in the following chapters. Some of these are designed for children with specific impairments such as hearing (Rumsey), vision (Bull, Gibson & Morrish), cerebral palsy (May), autism (Kennett), intellectual disabilities (Clunies-Ross; Pieterse) and two chapters pick up on the issue of language development, a concern in most programs for children with disabilities (Price & Bochner; Parsons, Smith & Bowman). Healey outlines a home-based intervention for socially-disadvantaged children, while others address two major problems of specific interest to service delivery in Australia; namely, the provision of services to rural communities (Hayes; Batcheler & Shaddock) and to migrant families (Croll). Issues in the mainstreaming of children with disabilities, also another topic of current interest in Australia, are addressed in a report about a consultant support service to teachers (Kemp) and finally there is a description of a service-delivery approach, centred round the concept of toys and play, which provides a range of services to a variety of children; the Noah's Ark Toy Library (Farrell & Glue).

The Contribution of tertiary institutions

Two projects which have had a noticeable influence on early intervention services for children with disabilities in Australia are the Down Syndrome Program at Macquarie University (Pieterse) and the E.P.I.C. program at Preston Institute of Technology in Victoria (Clunies-Ross). Beginning in 1974/75, these programs had a number of important effects on the provision of early intervention for young children with disabilities. First, they raised the expectations for children with Down Syndrome by demonstrating increased developmental progress for the children in the programs. This had a ripple effect on services for other children with developmental disabilities. Secondly, they demonstrated the importance of the educational/therapeutic model and the value of trained teachers and therapists in the intervention process. Finally, both centres promoted parents's roles as partners with professionals in the intervention process, together with the possibility of integrating many of the children into regular preschools (Pieterse & Center, 1984; Hudson & Clunies-Ross, 1984). These projects exemplify the important role which tertiary institutions have undertaken in promoting quality early intervention in Australia, through both research (Clunies-Ross, 1976, 1979, Hudson & Clunies-Ross, 1984) and curriculum development (Cairns & Pieterse, 1984; Pieterse, Cairns, Treloar, 1986). Subsequently, other university and college-affiliated projects have contributed to early intervention by their research and development activities; these have helped to maintain the high quality of early intervention in Australia, as seen in the chapters by Price and Bochner (Macquarie University), Leach, Swerisson and Leach (Murdoch University), Pratt and Grieve (University of Western Australia), Leeson and Opolsky (South Australian College of Advanced Education), Batchler and Shaddock (University of New England), Parsons, Smith and Bowman (La Trobe University).

Centre versus home-based programs

The early models which initiated the educational thrust in early intervention for intellectually-impaired children set the scene for centre-based programs staffed by qualified teachers and therapists, an approach reflecting the popular American models of Hayden and Dimitriev in Seattle and Bricker in Oregon. In contrast, the home-based English models used either professionally-supervised but unqualified teachers who implemented an adaptation of the Portage model, or a form of intervention based on an extension of the home-visit by a trained nurse, followed by special school placement at around the ages of 2-3 years. While Australian programs have tended to follow a centre-based model, the importance of parental involvement has not been underestimated. The centre- versus home-based service debate frequently misses the essential issue of whether the parents are really involved in the program, given the support and skills which they need to help maintain their child's development. It is worth noting that most of the programs described in following chapters recognise both the importance of parent participation in early intervention and the establishment of home-based programs, where necessary, to meet parental needs.

Changing services

Historically, services have long been available in Australia for people who are blind, deaf, cerebral palsied or autistic, but with the educational thrust in the mid nineteen-seventies, many of these services broadened the scope of their programs, by accepting children at an earlier age, and providing input through a multi-disciplinary team approach. Recognition of the importance of early language training for the child with a hearing impairment led to the provision of services to the preschool deaf child. Rumsey identifies current approaches to the teaching of the deaf and outlines the variety of services now available in New South Wales. A brief outline of recent research in this field is presented, but debate on the respective values of the oral/aural issue is dealt with briefly by Thorncraft in Part 3 of the book. The Royal Society for the Blind in Victoria provide help for visually-impaired children and their parents in that State (Bull, Gibson & Morrish). As with learning impairment, early diagnosis and parent participation are emphasised and early intervention is viewed as part of a range of services leading to integration into society at all levels. Again, parental involvement is seen as vital in the treatment of autism and cerebral palsy (Kennett, May). Services may be brought to the child and parent in the home, or provided in a centre-based program. Kennett points out the value of early identification and a thorough assessment of the child with autism in order to match a program to each child's unique cluster of behaviours, many of which would be too difficult for the parent to manage at home without the support of the home-management team. May notes that the restrictions placed on the child by cerebral palsy may lead to experiential deprivation. This may be counteracted by means of the services of the full multi-disciplinary team, although physiotherapy may be the major treatment required in the early stages.

The problem of language acquisition for children with disabilities is a recurring issue through all of the chapters in this section of the book. This subject is dealt with by two teams, who each present an alternative to the traditional speech pathologist's clinical approach. One is a centre-based program for parent and child (Price & Bochner), the other outlines holiday camps run in Victoria for children with a range of language difficulties (Parsons, Smith and Bowman). These chapters present theoretical and practical arguments for these types of service, both of which are aimed at improving communication skills through the natural interaction between parents and child. Parsons, Smith & Bowman claim that their approach avoids the artificial clinic setting in favour of a naturalistic situation where children may be more accurately assessed, and where natural social contingencies occur. The camps are staffed, and follow-up provided, by a trans-disciplinary team. Dealing with younger children, Price and Bochner encourage communication skills through individual, and group play activities and, especially, between parent and child.

The issue of parent involvement is also addressed by Croll in her description of an intervention service for migrant families with a developmentally-delayed child. This is a home-based service which attempts to meet major difficulties among inner-city migrant families who, because of language and cultural barriers, tend not to use available social and medical services. With the large migrant population of Australia and the government policy of multiculturalism, care must be taken to understand the culture background of these families in order to ensure that effective services are brought to their disabled children.

Healey outlines a home-based teaching service in a low socio-economic outer suburban area of Sydney. This is the only chapter in the collection which is concerned with children not identified as disabled. Healey recalls her experiences as a home-visiting teacher in a larger program (the Mount Druitt Early Childhood Project) which was intended to provide an enriched preschool experience to children who might be socially disadvantaged. The Home-based Program was one of five experimental preschool programs in the project; the others were preschool programs, each with a different theoretical approach to teaching. This chapter is included because it is representative of services provided for a disadvantaged, rather than a disabled group. In addition, it provided a home-based parent-oriented approach, thus reflecting one of the issues identified in this volume; namely the 'parents as partners' approach to early intervention. As Bettison points out in the first chapter of this book, most of the services identified in Australia tend to be centre-based. Several reasons can be suggested for this trend:

(a) similar social services are usually centre-based (e.g. the infant health sister's clinic in suburban shopping centres).

(b) the Australian housewife usually shops at, or regularly visits her local suburban shopping centre.

(c) our temperate climate means that children need not be confined to the house and can be taken to centre-based services.

A centre-based service appears, therefore, to be congruent with the Australian lifestyle. However, arrangements should be sufficiently flexible to cater for less mobile groups, such as the inner city migrant groups, who are unwilling to attend centre-based programs, or other families who cannot, or do not, wish to bring their children to centres, as described in the Healey study.

Considering its land area, Australia's population is highly urbanised. The majority of people live in sprawling suburbs around the main cities and along the coastal strips. Service delivery with low incidence problems such as developmental disabilities to isolated rural populations is a concern, as Batchler and Shaddock point out: 'Country people face unique difficulties in early intervention programs' with 'problems of distances, lack of transport' etc. Hayes also identifies the additional problems of recruiting and retaining qualified staff. The strength of the Gympie model that he describes, is that it pulls together the cooperative efforts of several organisations in a provincial town in Queensland, resulting in a practical service model which might be emulated by other small towns or rural districts. A relatively inexpensive, but effective and creative use of public facilities is shown in the design of the Tenterfield model, in which teleconferencing is used to provide support to teachers who are integrating disabled children into their preschools (Batchler & Shaddock).

Most contributors to this collection of papers identify mainstreaming or integration as a prime objective of their services. The need for support services to maintain disabled children in regular preschools is the subject of Kemp's description of a service available to the preschools established by the N.S.W. Department of Education in disadvantaged areas. These children are frequently not identified until they enrol at the local preschool and the service described by Kemp is an important development within the context of this large government department.

Finally, no description of early intervention services for children with disabilities would be complete without reference to the toy library, an organisation which began with the purpose of providing toys for disadvantaged children, but which has gone on to offer a wide range of services to handicapped children and their parents. Although structured programs with clearly defined objectives are still recognised as an important attribute of effective programming, the current research literature is moving back to its appreciation of play as the natural process by which parents and children interact, and as a natural framework for intervention. These authors, Farrell and Glue, originated the toy library movement in Australia and are at present the co-directors of the Victorian service.

The following chapters offer a rich variety of approaches to the common problems of providing affective early intervention for children with disabilities, in ways which meet different families needs in the context of the Australian culture. At the same time important issues of integration, early identification and assessment, the transdisciplinary approach and parental involvement are revealed.

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Chapter 10

THE DOWN SYNDROME PROGRAM AT MACQUARIE UNIVERSITY: A MODEL EARLY INTERVENTION PROGRAM

Moira Pieterse

Some of the most clear demonstrations of the effect of environmental conditions on the intelligence of young handicapped children has been provided by studies that involved a comparison between the developmental levels achieved by institutionalised and home-reared children with Down Syndrome (e.g. Ludlow & Allen, 1979). Such interest in environmental influences on intelligence was stimulated by the work of McVicar Hunt and Bloom in the early sixties. McVicar Hunt's (1961) challenge to the concept of fixed intelligence was supported by the evidence of Skeels and Dye's well known study of severely deprived children reared in an orphanage and the impact on their development and later adult status by removal to a more caring interactive environment (Skeels, 1966). Bloom's (1964) comprehensive review of child development research, argued that experience has its greatest effect during periods of rapid change such as the first years of life. He claimed that 50% of intelligence measured at the age of seventeen is fully developed by the age of four. In this climate of interest in the effects of environmental stimulation in early childhood, Jean Piaget's concept of intelligence was well received. His theory maintained that all children progress through the same stages of cognitive development but that the quality of learning opportunities in a child's environment will affect when and how those stages are reached (Piaget, 1952; Flavell 1977).

Attention to the impact of the environment on development in early childhood, allied with concern about the problems of socially disadvantaged, especially black children, in the U.S.A., stimulated passage of the Head Start legislation in 1964. This program attempted to counteract the effects of a poor environment by providing preschool education for children from disadvantaged populations. Although initial research on the effectiveness of the program was not promising (e.g. Gray & Klaus, 1970), subsequent long-term studies suggested that Head Start had a significant impact on its participants (Lazar & Darlington, 1982). However, a more significant result from the work done in Head Start was that it stimulated further interest in the possibilities of intervention for children who, because they were organically or biologically impaired, might also be environmentally deprived as a result of the limitations inherent in their impairments and disabilities.

The early intervention programs developed at this time for use with disabled children based their initial approach on factors that had been identified as being essential in programs designed for disadvantaged children. Research had demonstrated that effective Head Start programs had four elements in common; specifically they:

(i) provided a structured program with clearly defined objectives;
(ii) presented a consistent and theoretically justifiable teaching approach;
(iii) involved parents in decision-making and planning;
(iv) anticipated the skills needed for school and prepared the children for it.

These factors were also deemed important for disabled children, but because the children were organically impaired, other elements were also considered to be essential, including, for example, the involvement of therapists in a transdisciplinary model of service delivery, together with more extensive parental involvement in intervention from the time the disability was identified. Early intervention programs such as the Portage Program (Shearer & Shearer, 1972) and the Down Syndrome Program at the University of Washington, Seattle (Hayden & Dmitriev, 1975), provided leadership in the U.S.A. in the investigation of ways and means to provide disabled children with more stimulating experiences, and to equip them with skills which would enable them to enjoy a more normal life style. This report provides details of an Australian early intervention project, the Macquarie Down Syndrome Program at Macquarie University in Sydney that was strongly influenced, in its initial planning, by the development of programs such as these in the U.S.A.

THE EFFICACY DEBATE

Despite the fact that early intervention programs for organically- or biologically-impaired infants are now widespread and most people are convinced of their efficacy, there are few well-documented studies of their effects on the development of children with disabilities and research on their efficacy remains equivocal. For example, in a comprehensive review of 49 studies over the years 1967-1980, Dunst and Rheingrover concluded that there was little scientific evidence to support the contention that early intervention is efficacious with biologically-impaired infants (1981). However these reviewers counteracted this statement, making it explicit that they did not conclude that early intervention does not work; rather, that the experimental designs of the studies reviewed did not meet rigorous experimental research standards. Although research on the efficacy of early intervention is beset by methodological problems and the literature abounds with statements calling for more well-controlled and well-implemented research, (e.g. Bickman & Weatherford, 1986) at the same time, guarded claims for its efficacy are made; for example, that 'early intervention appears to accelerate their development', that 'long term gains appear to be maintained' (Bailey & Wolery, 1984, p.21). Indeed, there are tentative results that show more independent functioning, prevention of secondary handicaps, maintenance of gains into later childhood and less need for special education services. However, the most notable benefit is seen in the improved quality of life of the parents and families of handicapped children. Apparently, early intervention enables the achievement of a positive mode of interaction with the handicapped child, more positive expectations and social support for the families. As a parent of a Down Syndrome child commented on graduating from the program: 'The trouble with having a handicapped child is that you never know what to expect of your child. In the program, I was shown what she was capable of doing next and how to help her get there, so she became as rewarding to me as my other child.'

The efficacy debate about the value of early intervention can be reduced to two basic but interdependent issues: (a) what are the essential components in the effective programs? and (b) what are the most appropriate measures to evaluate the effects of early intervention?

(a) Characteristics of effective programs

Research into intervention for socio-economically disadvantaged preschool children isolated the essential characteristics of effective programs for those children. The important Westinghouse Study of Head Start showed that the short-term (summer) programs produced only short-term cognitive gains, but the full year program had effects on cognitive development which maintained up to grade 3 in elementary school (Cicirelli, Evans & Schiller, 1970). Follow up studies of model programs for socially disadvantaged children (i.e. well designed and well structured programs, with clearly defined objectives and instructional design which provided follow-through support into school) showed that the children had improved in performance and maintained their basic skills into school (Evans, 1975). Lasting effects of early intervention for these children showed that they were less likely to need special education later, or to repeat classes, and that their parents had higher achievement aspirations for them (Lazar & Darlington, 1979). Bronfenbrenner (1975) also noted that parent involvement was necessary if the gains were to maintain. These results provided guidelines for establishing early intervention for biologically-impaired children. It was hypothesised that highly structured and individualised programming, effective teaching strategies, major emphasis on language, low staff-student ratios and parent involvement, would also be important for biologically-impaired children. Subsequent research has reaffirmed the emphasis on structured programs (White & Casto, 1985) and generally supports the importance of parental involvement and the need to start as early as possible. Moore, Fredericks and Baldwin (1981) in Oregon and Clunies-Ross (1979) in Australia demonstrated that children with earlier and longer preschool experience were superior to those who began later and, although some recent research is equivocal on the parental factor, (White & Casto, 1985) it is logical to assume that parental involvement is important, because parents (a) have most contact with disabled infants, and (b) can provide the opportunities in the home for generalisation of skills. Indeed, emphasis placed on parent training is important whether the intervention program is conducted in the home, in a centre or in a combination of these service models. Support for parental involvement in early intervention also comes from the research into early language development, which notes that parents who involve themselves in stimulating play interaction with their infants are likely to have children with better language (Ainsworth, Blehar, Waters & Wall, 1978; Ainsworth, 1979).

In summary, therefore, it appears that the most important characteristics of effective early intervention programs for developmentally disabled children, are that they:

(i) have a structured goal-oriented approach with a clear-cut instructional model;
(ii) start as early as the disability is identified;
(iii) involve the parents in the decision making and the teaching process;
(iv) place importance on language development; and
(v) include an interdisciplinary service model.

(b) Program evaluation

As previously noted, the literature abounds with discussions on the problems of demonstrating efficacy in early intervention (see Bickman & Weatherford, 1986) and the debate continues regarding the most appropriate measures to use. The earlier studies used measures of child performance such as intelligence test scores or developmental quotients. Typical of these were the following reports: in 1981 Bricker demonstrated the efficacy of an early intervention program with measures of child performance over two years with a battery of normative and criterion-referenced tests (Bricker & Sheehan, 1981). In the same year, Moore, Fredericks and Baldwin (1981) reported long-term effects in early childhood education on a trainable mentally-retarded population by examining data from a criterion-referenced test (The Oregon Student Performance Record), as well as parent and teacher ratings, to demonstrate that children with at least 2 years of early intervention were subsequently more competent in school. Other measures used to demonstrate the effects of early intervention programs in the early 1980's also included school achievement tests, parent and teacher questionnaires. There were also indices of the impact of early intervention on the future life style of the child, such as whether he or she was subsequently mainstreamed or needed special education services (Karnes, Schwedel, Lewis, Ratts & Esry, 1981).

At present there is a dissatisfaction with the use of child performance measures as indicators of effective intervention and a shift in emphasis is apparent towards evidence of improved family functioning and ecologically relevant outcome measures as the important measures of effective early intervention. Social network theory and ecological psychology are used as a basis for proposing a broader-based measure of efficacy of early intervention (Dunst, 1986; Fewell & Vadasy, 1987). Regular evaluations conducted in the Macquarie Program for Down Syndrome children reflect this functional approach to the evaluation of an intervention. One study evaluated the appropriate play and social interaction of the children when integrated into regular preschools and another used sociograms of the children in regular schools in order to evaluate the social acceptance of graduates of the early intervention programs into mainstream classes (Pieterse & Cairns, 1977, Pieterse & Center, 1984a; 1984b).

The Macquarie Program has used normative and criterion-referenced tests of child development to demonstrate the efficacy of the intervention but has also included broader measures such as sociograms and teacher's ratings of social performance in mainstream schools, normed and class-based tests of reading and maths, as illustrated in the following report on the program.

A Model Program

Following a preliminary investigation of developmental programming for infants with Down Syndrome (Pieterse, 1978), an early intervention classroom was established at Macquarie University in Sydney in 1975. Based on the Seattle program (Hayden & Dmitriev, 1975) this was intended to be an exemplary program for children with Down Syndrome. As there was no early educational intervention in Australia at that time, it was important to explore how a service could be provided and to demonstrate that the children would benefit significantly from intervention. The main target of the research project was, therefore, to develop a model for early intervention which would be viable, economically feasible and optimally effective within the Australian context.

Although news had been brought back to Australia of innovations in early intervention with intellectually handicapped children in the U.S.A., there was little information initially available regarding the methods used in these programs. The new subdiscipline of Special Education had introduced aspects of instructional technology with practical relevance to this issue — namely, the behavioural model of learning strategies, the match-to-sample method of concept acquisition, the task-analysis model of curriculum construction which could be adapted to this age group by studying the sequential steps of normal development. Positive expectations of normalisation, a detailed sequenced curriculum, and the teaching strategies derived from the behavioural model became the basic principles of the program. These were complemented by an ongoing review of relevant research literature and by continuous revision of the program on the basis of data collected in the classroom from the various methods that were trialled (Pieterse, 1978).

The subjects in the model research program were limited to children with Down Syndrome. This was done for the following reasons:

(i) Down Syndrome can be reliably identified at birth by means of a chromosome test;
(ii) people with Down Syndrome constitute the largest percentage of persons identified as retarded;
(iii) there is excellent data on the performance of children with Down Syndrome against which the results of the intervention could be evaluated;
(iv) their intellectual handicap is of organic origin and a strong belief previously existed that environmental conditions, including education, made little difference to the intellectual development of children with genetic disorders;
(v) parents were being recommended that institutionalisation was the preferred treatment, with the result that about 50% of children with Down Syndrome were institutionalised soon after birth.
(vi) educational opportunities were not offered by the Department of Education in New South Wales for children with Down Syndrome until they were six years old even though most other young children could begin school at 4 years 9 months and the socially disadvantaged children even earlier.

Some of these points bear further elaboration. The availability of a reliable objective diagnosis which identified the extra chromosome and, consequently, the certainty of mental retardation for children with Down Syndrome, is a means of refuting possible cynics who might claim that subsequent improved performance was not the result of the intervention but could be attributed to errors in judgment in the initial diagnosis. For this reason, only infants with the regular Trisomy 21 form of Down Syndrome were accepted in the research program. Those whose chromosome test showed the mosaic pattern of affected and non-affected cells were excluded as these children are sometimes much less handicapped by their condition. Regular Trisomy 21 is seen in approximately 94% of persons with Down Syndrome.

Because it is usually recognised at birth, more children with Down Syndrome have been institutionalised early on the advice of medical practitioners. The resultant compounding effect of their restricted environment frequently caused severe retardation, self stimulation and emotional disturbance and aggravated the delay in language, motor and social skills.

In order to maintain an unbiased selection of subjects the policy concerning intake of children into the research program has been that, as the older children progress through the program, vacancies have been filled by a randomised intake of young infants. The practice has been to offer a place to the first parent who makes enquiries about admission to the program, whose infant is under four months of age, has regular Trisomy 21 and lives within commuting distance. The policy of taking infants sight unseen has resulted in the admission of children with a wide range of social and ethnic backgrounds, as well as the variety of medical complications which frequently accompany Down Syndrome; however, this procedure has been necessary in order to ensure that there are no accusations of selective intake.

It should be noted here that the primary purpose of the project was not to establish selective research on Down Syndrome, but to use this group of children to provide a convincing demonstration of the benefits of early education for all intellectually-handicapped children and their families. As suggested earlier, the main objective was, therefore:

> to develop an economically viable and effective model program;
>
> to apply the most up-to-date teaching strategies, in order to maintain the children's development as close to normal as possible in language, motor and social skill so that they could live a life as similar to their normal peer groups in their family situation;
>
> to integrate into regular preschool and at the age of five, if possible, to enter the regular school setting.

Normalisation has been a prime goal through the operation of the program.

THE MACQUARIE DOWN SYNDROME PROGRAM

The principles and practices in the Down Syndrome Model Program at Macquarie exemplify those identified in the research as being the most effective in early intervention. They include:

(i) education available to child and parent from the time of diagnosis of the child's impairment;
(ii) an individualised educational program designed for each child and family and therefore individual assessment and programming;
(iii) a data based program where the child's responses are graphed daily and teaching decisions based on the child's performance to ensure progress;
(iv) application of theoretically justified intervention strategies;
(v) emphasis on language and communication skills;
(vi) parental involvement support and training;
(vii) normalisation principles applied at all levels of programming, methods and outcomes.

There are usually 21 children in the Program, seven in each class, the number being dictated by the size of the facility. The infants (2-18 months) attend once a week for an individual session with teacher, therapist and parents; parental support and counselling is important at this stage. The toddlers (18-36 months) attend twice a week for a two and a half hour session which includes individual and group activities. Parent interaction training in communication and play occupies half the time. The preschool group of children (3-5 years) attend two and a half hours on three mornings a week (on the remaining days they attend local community preschools). At this stage they are introduced to preacademic skills, together with more advanced play and language activities. An individualised program is designed for all children based on the Developmental Skills Inventory (DSI) of the Macquarie Program for Developmentally Delayed Children, and T.E.L.L., the communication program, with objectives chosen on the basis of each child's needs. (Pieterse, Cairns & Treloar, 1986; Cairns & Pieterse, 1984).

On leaving the Centre, help is given to parents to find the most appropriate placement for the child. If possible, regular classroom placement is sought, especially if the school can offer some extra support; otherwise an integrated but separate class may be the least restrictive environment. Depending on the child's abilities, the available placement and parental wishes, a special school has occasionally been the chosen option.

Planning the classroom is also important for an optimal learning environment. Consideration is given to timetabling one-to-one teaching for the acquisition of new skills in small steps, with larger, group teaching for generalisation of skills. Careful parental training and advice to the preschool is given to ensure that newly acquired skills are generalised and maintained into home and preschool environments. Selecting toys designed for a child's level of ability induces successful play skills and avoids frustration. Activities are planned which offer opportunities for interaction and spontaneous language. If possible, non-handicapped brothers and sisters are included in play as this offers good role models in the program classroom and encourages continued interaction at home.

Developing the Curriculum

The first task in designing an intervention program in special education is to determine the skills which the child needs to master and the sequence in which those skills should be taught. Two major principles dictated the development of the curriculum and its subsequent revisions (Pieterse, Cairns & Treloar, 1986). These were, first, study of the normal development of infants and children as a key to the understanding of the sequencing of tasks, and secondly, the functional aspects dictated by a strong conviction towards normalisation, a conviction which set the mainstreaming in regular preschool and school classes as the optimal goal (incidentally, a goal which was considered to be totally unrealistic by education authorities at the time of the program's inception).

Research has consistently demonstrated that handicapped children progress through the same developmental sequences as non-handicapped children (Dunst, 1976), and, especially for the very young children, a developmental basis for assessment is preferable (Bailey & Wolery, 1984). The breakdown and sequencing of items in the Macquarie curriculum was accomplished through the study of 15 norm-referenced tests such as the Wechsler, Binet, Bayley and so on (Cohen & Gross, 1979). These tests were used and further analysed to obtain sufficient small steps to demonstrate improvements in children's performance over three-monthly assessments and to validate the sequences of the small steps (Pieterse, 1978).

In accordance with the goal of normalisation, items were also included in the Developmental Skills Inventory from a survey conducted with preschool teachers and regular classroom teachers who had been asked to identify the skills and behaviours which would be expected of children entering their schools. These teachers in regular schools were concerned that the disabled children not only had basic toileting, dressing and self care behaviour, but that they could pay attention in a group for a reasonable period, follow 2- and 3-part instructions, work independently, play interactively and have basic communication skills. These functional behaviours were task analysed and sequenced, and the preliminary skills introduced at an early stage in the developmental checklists.

Using development sequences as a clue to the analysis of the small steps and a functional approach dictated by a commitment to normalisation, the curriculum was assembled and revised several times. The combination of the developmental and functional approach was used in developing individualised educational programs for the children. As Bailey and Wolery state 'the answer to the question of functional versus developmental sequences is not an either-or response' (1984, p.33). A combination of both is important in effective programming for delayed or disabled children.

Revisions of the curriculum over time included a changed approach to learning language skills. We were greatly influenced by the the idea of pragmatics in the development of communication skills and by the transactional approach to early language training. (McLean & Snyder McLean, 1979). While the match-select-label teaching strategy proved invaluable as a means of developing language concepts, the transactional approach directed towards the child's need to communicate appears to be the answer to the problem of getting the children to talk and communicate spontaneously. It follows naturally and logically from the mother-child interaction approach which dominates our work with infants. It relies on similar turn-taking, waiting and responding, tuning into the child's behaviours, an interactional process which we were already using to help the mother relate to the baby from the first few months. The result of the research in language development was a separate curriculum **T.E.L.L.: A communication Program** (Cairns & Pieterse, 1984). T.E.L.L. combines the syntactic, semantic and pragmatics components of language and offers an effective method of assessing a preverbal and verbal child's early communication skills and analysing them through a series of flowcharts in order to identify his/her language needs. Teaching strategies involve helping parents to utilise their own and the child's environment to stimulate interaction and communication. The transactional language methods of T.E.L.L. are also included in the revised versions of the Macquarie Program for Developmentally Delayed Children (Pieterse et al., 1986).

Other curriculum areas which have been influenced by a study of recent research include motor development, cognitive functioning and teaching strategies. Motor development has been influenced by research in pediatric physiotherapy (Harris, 1981). The emphasis has changed from a milestone or end-objective approach to a concern with the process of movement, where the focus becomes the quality of ultimate functioning, in preference to striving towards the milestones of sitting, standing and walking. Emphasising the end objectives rather than the process frequently led to poor posture and awkward abnormal body movements, a result not compatible with the primary goal of normalisation. This new emphasis is still under investigation. The curriculum also acknowledges the theory-based cognitive developmental approach and includes items from the Piagetian sequences of sensori-motor development. Some of these are not teachable goals, but are included for observation purposes. Other cognitive developmental items respond to intervention; these include imitation skills, object permanence and means-end, abilities which may be facilitated by enriching the child's environment with the right opportunities at the right time. The value of two important teaching strategies for delayed children are also recognised: (a) the applied behaviour analysis techniques, and (b) the match-to-sample concept acquisition strategy. Items are included which identify objectives incorporating these strategies — such as the matching, selecting and labelling to an increasing number of discrimination tasks and the use of appropriate prompting, modelling and reinforcing.

The goal of our efforts in writing the Macquarie Program for Developmentally Delayed Children (Pieterse et al., 1986) has been to produce a curriculum suitable for the Australian population which incorporated the most recent research in early childhood special education. The research classroom is used as a means of refining the curriculum and teaching strategies. The Macquarie Program for developmentally delayed children (Pieterse et al.,1986) consists of a teachers handbook describing its principles and how to use it: how to assess a child, set up a program, teach the child, and keep data on the effectiveness of the intervention. It includes a new feature, the adult/child observation guides, which focus on the quality of interactions between parents or teacher and child. The checklist (Developmental

Skills Inventory) is contained in five booklets, one for each year of normal development, which cover gross and fine motor, cognitive, language and personal-social skills. The method and materials needed for assessment and a criterion for success are outlined in the accompanying manual. There are other supplementary programs on teaching reading, and writing and number skills. The Macquarie Program is the most well known and widely used curriculum for early intervention in Australia.

Preacademic skills

Persons with Down Syndrome are habitually labelled as 'trainable or ineducable' on the supposition that they are incapable of learning academic skills. At the Down Syndrome Program at Macquarie University, children have been introduced to basic reading, writing and number skills as early as three and four years of age. Essentially this happened by the children making their own learning pace through the preliminary sequences of academic skills and by our refusal to set limits on our expectations for them. Reading is usually introduced to children who have a competent five-or six-year old's language ability, but with the children in the program, the printed word is introduced as part of the language acquisition process, and even children who are speaking at basically a one-word level are able to recognise those words on a printed flash card. Indeed, the presentation of the printed stimulus provides a visual prompt when presented in conjunction with the spoken word and this may be the reason why it appears to facilitate the language acquisition of children, many of whom are hearing impaired. (up to 70% of children with Down Syndrome have hearing difficulties and research has shown that their rate of learning is improved by visual presentation rather than auditory presentation of the stimulus.)

The Reading Program uses the match-select-label learning paradigm — and introduces meaningful words from the child's own language — family names and commonly used objects and actions. The whole word approach is supplemented by word attack skills of decoding once the child has 50 or more words. An activity which takes no more than five minutes of instruction on the three days in which the child attends the program centre and is practised briefly at home by the parents has had an enormous effect by changing the attitudes of parents and teachers to the learning potential of children with Down Syndrome. Parents are proud of their children's accomplishments in reading, and teachers are more likely to accept the child into a regular class and generally offer the child more opportunities to learn because of the evidence that they can learn an academic skill and are therefore not 'ineducable'.

In the first Progress Report, it was recorded that four children (average age 3 years 10 months) were reading an average of 25 words (Thorley, Pieterse, Cairns & Redmond, 1976). One year later, several of those children had over 125 words; Wilson, aged 4 years 7 months had 180+ words (Pieterse & Cairns, 1977). Subsequent reports showed that the children maintained their reading skills. Some years later, as is evident in Table 1, when a group of eight children had progressed into regular school, their average reading age was within a year of their chronological age and they were ranked within the reading abilities of their classmates in the regular classroom (Pieterse & Center, 1984a). Their comprehension was also assessed and found to be satisfactory. At the intervention program, comprehension is ensured by keeping reading as an integral part of the language training. In other preacademic areas, e.g. number and writing, our objective is, that the children will be able to count out a set of objects up to ten correctly and in writing, that they should be able to print their own names by the time they are five years old.

TABLE 1

Chronological and reading ages of eight Down Syndrome Children in regular classrooms

Name	Chronological Age	Schonell * reading age	Neale reading age +
M	9.4	7.2	7.8
R	8.9	7.2	7.2
W	8.7	9.4	9.3
A	8.0	6.1	7.0
D	7.8	8.0	7.2
D	7.3	6.1	6.1
M	7.3	6.4	—
J	7.2	6.0	—

* Schonell Graded Word Reading Test No.1981

+ Neale Analysis of Reading Ability

(Pieterse & Center, 1984a)

Preschool Integration

Giving the children the opportunity to gain pre-academic skills, as well as their essential language, personal skills and social behaviours, facilitates their chances of being mainstreamed into regular schools. The integration process begins earlier, however, with the children's placement in normal community preschools from the age of three, for one or two days a week. Support and advice are offered to the preschool staff. Play skills and social skills acquired in the Program setting are generalised into the preschool as the children are encouraged to interact with other children. A recent study of the integration of these children in preschool demonstrated that they were accepted by their peers and that good interaction occurred (Pieterse & Cairns, 1987). Earlier identification and instruction in the functional skills needed for preschool has proved to be worthwhile, as all of the children have been successfully integrated into community preschools. This experience has also developed the children's social skills, providing opportunities to apply and extend skills learned in the Program into the preschools and preparing them for regular primary schools.

Integration into regular schools

Eight of the first nine home-based children who graduated from the research program at aged five were placed in regular schools with support provided by a Consultant funded by the Program. Research undertaken to investigate the efficacy of this initiative showed that:

> 'The eight D.S. children who were integrated into their local schools were studied some time later. The results of cognitive, academic and social measures indicated that the children functioned within the mild rather than the moderate range of mental retardation and that they were within the range of variability tolerated in a regular classroom for social skills and for both oral reading and reading comprehension. On tests of mathematical achievement all but one child scored in the lowest percentile ranking. These results suggest that, following early intervention and with specialist support, Down Syndrome children can be successfully integrated into regular classes at least until fourth grade primary school (Pieterse & Center, 1984a, p.11).'

Two years later there were 12 integrated children and the research showed that, although maths remained a problem, they still maintained their reading and social skills in regular classrooms (Pieterse & Center, 1984b). However, many of the children were subsequently unable to maintain in the regular classes in upper primary grades, particularly when the regular consultant support provided from the research project had to be discontinued for lack of funds — and other support was not available.

In the following section, results are reported from three studies of children's progress, both within the Program and in subsequent years at school.

Study 1

As this was the first educational intervention program in Australia, it was possible to test and retest, after approximately 12 months, the developmental progress of a group of randomly selected children with Down Syndrome (regular Trisomy 21) (experimental group) and group of children with Down Syndrome from a similar background (control group) who were receiving the occasional therapy services available to families at that time but were not involved in an intensive early intervention program.

Both groups of children were tested on the Denver Developmental Screening Test and a developmental index obtained (Pieterse, 1978). The results of this testing are set out in Table 2. These show that after at least one year in the intervention Program the experimental group was superior to the control group in language, motor and personal/social skills.

Table 2
Significant differences between experimental and control groups of preschool Down Syndrome children

Age in months	Personal Social	Fine motor	Language	Gross motor	Exp. n	Con. n
12+	+	+	+	+	8	5
18+	+	+	+	+	15	7
30+	+	+	+	+	14	6
42+	na*	+	+	+	17	7
54-66	na*	+	+	+	3	5

+ Signifance at .05 (Mann Whitney U Test) * limit of test used

Study 2

Results of a review of annual assessments over six years using the U.P.A.S (Haring et al., 1981) for children in the program aged 18 months to 6 years are set out in Table 3. These show an average achievement of 80-100% of normal skills. These results demonstrate that these children, who might otherwise have been expected to function at a moderately handicapped level achieving only 40-50% of normal behaviour, could be taught the functional behaviours of normal children of the same age and achieve from 78% to 100% of these skills (Pieterse, 1985).

TABLE 3
Distribution of U.P.A.S.developmental scores for intervention groups over six years. Mean percentage of normal skills

Year	n	Mean age	Pre-academic	Communication	Personal/ Social	Gross motor
1979	14	46m	na*	78.0	101.0	83.0
1980	12	43m	na*	78.0	96.6	97.0
1981	11	48m	na*	80.0	99.0	93.0
1982	13	44m	88.0	85.0	106.0	93.0
1983	13	47m	87.0	84.0	115.0	98.0
1984	13	42m	89.5	82.5	111.0	96.0
Mean		45m	88.17	81.25	104.77	93.0

* not available — used U.P.A.S lst edition

Study 3

This study used the successful mainstreaming of the first graduates of the program as a measure of effectiveness of the early intervention program. Test results indicated that the eight children were socially integrated and had reading abilities within the range of competence of their peers in a regular class (Pieterse & Center, 1984a). Two years later, these eight and the next four children who graduated from the intervention program were again evaluated on the same measures and showed similar results for reading skills and social acceptances (Pieterse & Center, 1984b). Clearly these children were successfully mainstreamed and did not require extensive special education services at this level of schooling.

Parental Involvement

It has always been recognised that the early intervention program is an important support system for the parents. The teachers and therapists in the Program recognise and understand the parents' initial shock and grief and then provide ongoing support to the family. Introducing the transactional approach of the language program brought increased awareness of the importance of the parents' feelings about themselves and their child, as it became obvious to the researchers that the happy parents were the ones who were able to play and communicate with their child and who were sufficiently relaxed to wait and anticipate the child's communicative initiatives and thus improve the child's language skills. This important factor has been reported lately by other researchers; for example, Mahoney, Finger and Powell (1985) found in their study of mentally-retarded children that the maternal behaviours which were positively related to the children's cognitive functioning were sensitivity to the child's state, enjoyment, responsiveness and appropriate teaching. Similarly, Dunst (1985) found that positive family support related to facilitating and engaging maternal interaction styles. Clearly family functioning plays a significant role with the child's life and can be assisted by the support of an early intervention program.

The Early Education Clinic — A Service Program

In 1979 an early intervention program was established at Cremorne, a suburb of Sydney, with the help of the University Down Syndrome research unit. The Director of this project, Mrs Sandra Leonard, had trained in the Macquarie Program classroom and with the financial support of the NSW Department of Youth and Community Services, decided to establish a service program for the many extra families of children with Down Syndrome receiving casual help from the Macquarie University program and for other children with intellectual delays or disabilities. This was an opportunity to extend the use of the curriculum materials and teaching methods to the wider population of disabled children. Subsequently, with help of Mrs Betty Hook, another graduate trained at Macquarie, the centre moved to suitable premises in North Sydney and extended its service to Parramatta.

The early education clinic now provides a service to over 300 families per year, with children aged 0-5 years ranging from profoundly handicapped to some with mild delay, including at-risk premature babies. Approximately one third are children with Down Syndrome (Leonard, 1987). It is one of the largest early intervention services in New South Wales, assisting families in the Sydney-Parramatta metropolitan areas and in some country areas that have no local service. Employing teachers and therapists, it offers a service similar to the research program but adapted to the requirements of the more varied population of children and parents. For instance, although many parents can follow written program instructions and even take data on their children's progress, there are also parents who are themselves handicapped and/or illiterate. The clinic staff meet a wider range of family problems and children with behaviour problems than does the research unit, especially with handicapped children whose intervention was begun late and in whom inappropriate behaviours have developed. The Macquarie Program for Developmentally Delayed children curriculum is used for all children but needs adaptation for use with more profoundly handicapped children. Again the processes of task analysis and individual adaptation to the child's and parents' needs are employed.

An interesting observation made by Mrs Leonard after nine years of running this service, to which referrals may be made by parents as well as professionals, relates to her respect for parental observation of their children and supports the establishment of an educationally-oriented service. When parents refer their child to her services, often overriding medical advice, nine times out of ten she notes that the parents are correct and there is something wrong with the child; either a delay in one or more areas or severe social problems. These latter problems, some of which may be due to the parental handling of the child, are often not easily picked up in the consulting rooms of pediatricians.

CONCLUSIONS

Since the beginning of the Down Syndrome Program at Macquarie University in 1974, the growth in Australia of early intervention services to families with children who are delayed and disabled has been remarkable. It is part of the total revolution in opportunities for persons with disabilities in Australia and elsewhere. The Down Program at Macquarie played its part in this movement, helping to change the attitudes and expectations of society towards children with Down Syndrome and others like them by showing that these children were not ineducable and could attend regular schools and take part in community activities relevant to their age. The Program has served as a model for early intervention services in Australia. It has been visited, examined, praised and criticised, but has always stimulated services in education for young handicapped children. From a high of 50%, the institutionalisation of Down Syndrome infants in NSW has dropped to less than 5%. Parents in Australia are now given support to keep their children at home. Preschools encourage their integration and schools, both public and private, are offering more integrated education for children with Down Syndrome. The well researched and frequently revised Macquarie Program curriculum material has been used, borrowed, copied and even translated into Chinese, Thai, Indonesian and Dutch, and certainly has been a great help to many teachers, children and parents.

Parent involvement has been a high priority and special efforts have been made to help parents outside the program by producing videotape programs and materials such as the new Small Steps kit of videotape program and books. The group of parents of children attending the Down Syndrome program discovered the value of a parental support group and the need for advocacy for their children so they established the NSW Down Syndrome Association. Recently, this has grown to a National group.

The intervention methods used in the Program have responded to changes in current directions and the original behaviourist teaching methods have been broadened to accommodate a more interactional approach, especially in language development. Evaluation, originally on child measures, was broadened to examine the impact of the intervention on the child's interactions and performance in preschool, school and family. From the beginning, adherence to the principle of normalisation provided a functional priority to skills based on normal development. This is compatible with the trend over the last ten years to place an emphasis on functionality in most services to the handicapped.

The influence of the program has been felt outside Australia. In 1983, the Watchdog Program, a replicate program for English and Chinese children, was established in Hong Kong. Considerable time and effort has also gone into running inservice workshops in New South Wales and other Australian states and providing consultant and training services in Hong Kong, Thailand, Indonesia, England and Holland. The opportunities to visit overseas early intervention programs and to keep abreast of world wide research is a further reason for the existence of model programs and research centres such as the Down Program at Macquarie University which has had an important role in the changing opportunities for children with Down Syndrome, and others like them in Australia.

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Chapter 11

EARLY EDUCATION AND INTEGRATION FOR CHILDREN WITH INTELLECTUAL DISABILITIES

Some Results of a 10 Year EPIC

Graham G. Clunies-Ross

The Education Program for Infants and Children (EPIC) came into existence in 1976 as a result of a submission to the Commonwealth Government in 1974 for funds to establish a 'training and advisory centre for intellectually handicapped children (0-5 years of age) and their families'. The initial intake of 25 children included 17 with Down syndrome, four with cerebral palsy, three with unknown etiologies, and one classified as 'possibly autistic'. The ages of these children on enrolment ranged from three months to three years. The children were all listed on a Health Department register of 'retarded children awaiting services', and were referred to the program by the Health Department.

PROGRAM RATIONALE AND OVERVIEW

Two major goals stated for the program at the outset were

(a) to accelerate the development of infants and young children with intellectual disabilities so that they will approximate as closely as possible the developmental levels and achievements of their non-disabled peers,
and

(b) to provide training in child management and home teaching for parents of children with disabilities.

A third major goal added subsequently was

(c) to promote and facilitate the integration of children with intellectual disabilities into regular kindergartens, schools and the wider community.

To enable these goals to be realised EPIC has established systems for centre- and home-based instruction of children, parent training, and follow-through to support the integration of children into regular kindergartens and schools.

Comparative and evaluative studies with young socially disadvantaged and disabled children have delineated a number of essential requirements for effective early intervention (Bronfenbrenner, 1975; Karnes & Zehrbach, 1977). Included among the requisite components are: commencing intervention as early as possible in the child's life; involving parents in their child's education; using a structured framework for curriculum design and teaching; formulating curriculum objectives around normal developmental sequences; conducting frequent assessments of progress and performance, and using the data to reset objectives and evaluate teaching; having the program implemented by an integrated interdisciplinary staff team; and providing follow-through support for children as they advance beyond early intervention (Clunies-Ross, 1979).

Most families are referred to EPIC within three months of their child's birth, and commence almost immediately on home-based teaching mediated through the parent training program. In the majority of instances families are referred by a person involved with the birth or post-natal care of the child.

The curriculum consists of a comprehensive set of structured programs in the areas of language, cognitive, fine and gross motor, social, and self-care development. Both developmental and functional approaches have been taken in designing the curriculum. Normal developmental sequences provide the guidelines for formulating the major curriculum objectives up to the three year level of development. Within programs specific sequentially-ordered behavioural objectives have been determined by task-analysing the skills involved in achieving the more general objectives. Beyond the three year level, objectives increasingly focus on functional skills that will facilitate the child's integration into a regular school. The educational model which provides the framework for implementing the curriculum has been based largely on the concepts, principles, and strategies of applied behaviour analysis and direct instruction (Becker, Engelmann & Thomas, 1975a, b).

The children's progress towards the achievement of specific behavioural objectives is monitored continuously, usually in the form of frequency of response and/or percentage of correct responses. An 80-90% level of correct response is the usual criterion set for the achievement of individual curriculum steps. The sequential nature of the programming ensures that considerable post-criterion overlearning is built into the instruction. At approximately four-monthly intervals up to the developmental age of three years, each child is assessed on the Early Intervention Developmental Profile (EIDP) (Rogers & D'Eugenio, 1977; Rogers, D'Eugenio, Brown, Donovan, & Lynch, 1977). The EIDP provides the main source of norm-referenced data, but periodic assessments are also conducted with the Stanford-Binet, PPVT, and Reynell Developmental Language Scales.

Centre-based programs are implemented by an interdisciplinary staff team comprised of teachers, physiotherapists, speech therapist, play leader, psychologist, and parent volunteers. Home-based programs are conducted by parents under the supervision of a staff member. Visiting staff undertake the follow-through programs supporting integration of children into kindergartens and schools.

PROCEDURES

Enrolments

Following the initial intake of 25 children, requests to be included in EPIC increased rapidly and a waiting list had to be created. Since 1979, 78 children have been enrolled in the centre-based program each year. There is currently an average waiting time of 12 months to enter this program. In order to contain the waiting list to its present level, it has become necessary to restrict enrolment applications to children under 18 months of age. The only other criterion for enrolment is that the child is considered to be 'at risk' for developing a moderate level of intellectual disability. Application of these two criteria over the last four years has resulted in 95% of the clientele being families of children with Down syndrome.

Waiting list families and participants in the external service (families living in rural areas and others unable or ineligible to enter the centre-based program) undertake the parent training program. There are currently 31 families included in the parent program.

Regular kindergartens and schools enrolling EPIC children are invited to participate in the follow-through program. Each year over 50 primary schools and 25-30 kindergartens are offered this service.

Centre-based program

Children enrolled in this program attend one of two half-day sessions per week, and in each session they receive an average of 1.5 hours of prescribed instruction. For one hour each session a teacher works (usually individually) with the child, allocating approximately equal time to teaching language, cognitive, and fine motor tasks. Examples of task objectives are shown in Table 1. (A curriculum and instruction manual is being prepared for publication.)

During the other half-hour of specific instruction, a physiotherapist or speech therapist works with the child, focusing on, respectively, gross motor or language objectives. Following each teaching or therapy session, the staff member meets with the parent to review the work completed, demonstrate new activities, and suggest home teaching tasks for the ensuing week.

Table 1.

Examples of Language, Cognitive, and Fine Motor Objectives

Age (months)	Language	Cognitive	Fine Motor
0-6	Turns heads in direction of sounds	Use of objects to make noise	Can grasp object with both hands
	Imitates speech sounds	Finds partly hidden object	Bangs blocks together
6-12	Claps on verbal cue	Anticipates place of moving object	Pulls peg out of pegboard
	Imitates animal sounds	Attempts to imitate new sound	Marks with crayon on paper
12-18	Imitates words inexactly	Stacks objects above brim of cup	Places one object on top of another
	Names one object	Matches objects and pictures 1:1	Guides an object to hit target
18-24	Selects named objects 6:6 +	Imitates movements exactly	Places triangle into formboard 1:1
	Uses action words descriptively	Sorts red, yellow, blue, green 1:3	Draws vertical strokes after demonstration
24-30	Uses first name	Matches colours 1:6	Folds paper in imitation
	Understands two prepositions	Sorts big and little	Completes two piece puzzle
30-36	Uses three word sentences	Matches shapes 6:6	Snips with scissors
	Forms questions using a verb	Counts two objects	Identifies object by feeling it

For the remainder of the half-day session, the child is involved in individual or group play activities organised and supervised by the play leader and parent volunteers. Although most play routines are not formally prescribed, an emphasis is placed on the achievement of social objectives (e.g., initiation of social interaction, following directions, cooperative play and turn taking, cleaning up and putting away) as well as play skills.

Parent training and home-based programs

Families on the waiting list and external families attend the EPIC Centre at 4-6 weekly intervals (either individually or in small groups) to take part in the parent training program. This is conducted by a psychologist and a physiotherapist, and aims to provide parents with basic teaching and child management skills to enable them to undertake home teaching.

The format of the program is similar to the specific **focus plus controlled learning environment** training strategy described by Hudson (1982). At each session specific objectives are established for each child, with a sufficient number selected to extend through the interval until the family's next visit to the centre. The parents are given detailed written instructions about how to teach the sequence of behaviours leading up to the achievement of each objective, demonstrations of teaching methods, and feedback on their own teaching behaviour. They are encouraged to integrate home-teaching tasks into daily routines whenever possible. However, if this is not feasible, it is suggested that the equivalent of two 15-20 minute teaching sessions be conducted four or five days a week. Subsequent meetings at the centre begin with a review and evaluation of the previous home programs. The development of self-care behaviours (eating, toileting, and dressing skills) for children in the centre-based program is undertaken primarily through home-based teaching. Parents are provided with written instructions detailing the steps to be followed and methods of implementation. They are given data sheets on which to record their child's progress, and discuss these progress records weekly with a staff member (psychologist or teacher). The staff member supervising the home program is responsible for checking the reliability of the parents' collected data, and for assisting the parent to maintain the home program.

Home training is also used to promote generalisation and consolidation of skills being taught in centre-based programs. Staff provide parents with guidelines and materials for undertaking home-teaching during the periods between the child's attendance at the centre. It is suggested that parents try to integrate home-teaching activities with daily routines, or otherwise conduct the equivalent of at least one 15-20 minute session a day with their child.

Follow-through program

All children in the centre-based program and most of those participating in the external program are referred for placement in a regular kindergarten at about four years of age. In the majority of cases children are involved in EPIC and a kindergarten program concurrently for two years before entering school. A visiting teacher provides liaison between the two preschool programs, and assists kindergartens to undertake appropriate integration activities.

Primary and secondary schools enrolling EPIC 'graduates' are offered a follow-through program that includes four components: preparing the school for integration; assisting the school to develop effective instructional strategies for the child; conducting in-service workshops on applied behaviour analysis and direct instruction; assisting the school to monitor and evaluate integration strategies and outcomes. The first component begins about 6 months before the child enters the school and focuses particularly on the development of positive attitudes towards integration in the school. Teachers are informed about government education policies, the behaviour and development of children, models and strategies for integration, and successful practices in other schools. The other components of follow-through may occur at any time during, or continuously throughout, a child's schooling.

RESULTS OF RESEARCH STUDIES

Centre-based program

Two previous studies have reported the developmental progress of several groups of children with Down syndrome who had been involved in the program for between four months and two years (Clunies-Ross, 1979, 1981). Although in some of the groups examined the sample was small and the length of intervention quite short, a similar pattern of results emerged in each analysis. The development of all children was accelerated, with achievements at or above 'normal' levels being attained in a number of cases. An investigation of the relationship between age of commencement in the program and developmental progress indicated that younger children were advantaged because they entered the program at a higher developmental level, and then progressed at least as rapidly as older children.

In order to gain more extensive information about the progress of children entering the program at a very young age, an analysis was carried out of the first three years of development of all children with Down syndrome who commenced within eight months after birth. A search of the files revealed 42 children for whom sufficiently complete EIDP assessment data were available to be included in the analysis. The sample size was limited because the waiting list has resulted in most children being over 12 months of age when they enter the centre-based program.

Table 2 shows the mean developmental index (DI) scores for these 42 determined at approximately six-monthly intervals in each area of development measured by the EIDP. Birth to three years is the range covered by this norm-referenced instrument. The DIs were computed by dividing the child's assessed developmental skill level by his/her chronological age. A DI of 1.0 would indicate a normal or average level of development for the given chronological age.

Table 2. Mean DIs for 42 children with Down syndrome assessed at 6 month intervals

Mean age and range (in months)		Language	Social	Self Care	Cognitive	Fine Motor	Gross Motor
6.0	$\overline{X}$	.83	.76	.83	.82	.73	.70
(3-8)	SD	.14	.18	.15	.14	.16	.13
12.1	$\overline{X}$	.79	.81	.83	.80	.75	.66
(10-14)	SD	.14	.17	.12	.13	.15	.11
17.9	$\overline{X}$	.83	.89	.83	.84	.84	.64
(16-20)	SD	.12	.17	.11	.11	.13	.13
24.0	$\overline{X}$	.86	.98	.82	.90	.91	.73
(22-26)	SD	.12	.10	.10	.11	.10	.16
30.1	$\overline{X}$	.86	.97	.85	.93	.93	.76
(28-32)	SD	.10	.06	.10	.10	.08	.13
35.1	$\overline{X}$	.86	.96	.88	.95	.92	.78
(33-37)	SD	.09	.05	.08	.07	.06	.10

It may be seen that (a) an overall increase in mean DI occurred in each area of development, (b) the gradients of improvement were much steeper for social, cognitive, and fine motor development than for language and self-care, (c) a U-shaped gradient occurred for gross motor, (d) dips appeared at the 12 month level in language and cognitive, (e) a slight dip was apparent at 24 months for self-care, and (f) tailing off was evident to a minor extent in social after 24 months.

Parent training

The initial parent training programs at EPIC were short courses in child development and child management presented in a lecture-discussion format to groups of 12-15, backed up by homework exercises which the parents undertook with their children (Clunies-Ross, 1976; Griffin & Hudson, 1978). Although parents reported a high level of satisfaction with these courses, it became evident to the trainers that parents were not acquiring durable and generalisable teaching skills. There was clearly a need to investigate alternative training strategies.

A component analysis of training programs for parents at EPIC was carried out by Hudson (1982). A sample of 40 mothers of young children with Down syndrome (33), cerebral palsy (5), and other disabling conditions (2) were randomly allocated to one of four treatment groups: focus on specific target behaviours, specific focus plus the teaching of behavioural principles, specific focus plus controlled learning environment, or a wait- control group. The specific focus component consisted of giving the mothers detailed instruction about how to teach specific target behaviours. Adding the behavioural principles component involved providing parents with a short course in applied behaviour analysis as well as instructing them about the teaching of specific behaviours. In the controlled learning environment component the mothers' teaching of target behaviours was directly shaped through modelling, role playing and immediate feedback. The results of the study indicated clearly that it was necessary to include techniques that directly shaped the parents' behaviour in order for them to learn to be effective teachers of their children.

Follow-through

A study of 15 EPIC graduates enrolled in regular primary schools was reported by Hudson and Clunies-Ross (1984). The children were assessed on a wide range of measures which included norm-referenced tests of reading, language, and mathematics; teacher and parent ratings of academic achievement, adjustment, and peer acceptance; systematic observations of the children in the classroom and the playground; and sociometric data. It was found that most of the children had adjusted well to the classroom setting, and were well accepted by their peers. Academically, the progress of the children was more variable. The teachers and parents exhibited positive attitudes towards integration.

DISCUSSION

The data reported in Table 2 confirm the previous findings from this and other programs that systematic early education (incorporating the components of effective intervention described earlier) can accelerate markedly the development of infants and young children with Down syndrome (Clunies-Ross 1979, 1981; Hayden & Dmitriev,1975; Pieterse, 1979).

The present data, based on a larger sample and longer period of intervention, clarify and extend the results reported earlier for our centre-based program.

The earlier studies had suggested that the younger the age of the child, the higher their initial DI scores. This is important when considering the possibilities of early education for preventing the manifestation of significant degrees of intellectual disability. If the younger child's initially higher DIs can be maintained or increased, then prevention would have been achieved to some extent. A comparison of the Table 2 information with earlier data is revealing. The 1981 paper included DIs for 20 children as they progressed from 11 months to 35 months. The average DI for the group at 11 months was 0.63. In all six areas of development the groups was substantially lower in mean DI than the present sample was at 6 months. The earlier group's average DI at 35 months was 0.87; equivalent to the present sample's level at 24 months. Thus, the present findings highlight the preventive potential of intervention when commenced very early in the child's life.

The data in Table 2 give the impression that the developmental status of the children was flattening out towards the three year level. It is quite likely that the gradients of improvement in development were negatively accelerated. However, the trend in this set of data could be an artifact of the particular measuring instrument used, as 36 months is the ceiling on the EIDP. Certainly, the apparent tailing off in social development after 24 months was a statistical artifact of the test ceiling. Many children had passed most items on the social scale well before the age of three years. They therefore received DIs of greater than 1.0 early on, which then had to be reduced as they approached the age of 36 months.

The dip in mean DI evident at about the 12 month level in language and cognitive areas was due primarily to a temporary delay in estalishing basic imitation, particularly sound imitation, with a number of children. Several imitation items are included in both the language and cognitive scales of the EIDP between 6 and 15 months (approximately). The slight dip in self-care at 24 months appeared to reflect no more than chance variations in the assessment data.

As our previous research has indicated, children with Down syndrome are likely to be least advanced in the gross motor area during their early years. The drop in the developmental gradient evident during the 12-18 month period resulted entirely from the fact that most of the children did not walk alone until they were over the age of 18 months. Most of the gross motor items assessed in the CA 12-18 month range involved walking.

The outcomes of Hudson's (1982) parent training study underlined the necessity of making specific skill training the basis of home-teaching programs for parents. Our subsequent experiences have indicated that it is desirable to run refresher programs at regular intervals to ensure durability of parents' home-teaching skills. Further research is needed on the perennial question of generalisation. It is important to determine instructional strategies that will train parents to apply their teaching skills to tasks outside and beyond the early education curriculum.

Very little Australian research has been concerned with the integration of children with intellectual disabilities into regular schools, and negligible resources have been made available to support follow-through programs. Given that a major goal of early intervention is to prepare children, families, and schools for integration, it is imperative that the highest priority be allocated to research and development in this area.

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Chapter 12

HEARING, HEARING LOSS AND EARLY INTERVENTION

Catherine Rumsey

Hearing impairment is an invisible handicap. There are no obviously deformed limbs nor any immediately obvious behavioural malfunctions. Yet it has the potential to be educationally and socially devastating. Hearing is as effortless a function as breathing, it is always present and cannot be turned on and off at will. By constantly monitoring the environment, hearing contributes to an individual's sense of well being. Most importantly hearing is the sense which receives the sound of the human voice and through that voice the language of the culture within which the individual grows (Levine, 1982; Myklebust, 1960). Basic needs and emotions can be expressed by such nonverbal means as 'body language'. However, it is the developed language, that is, a rule governed system of words or signs which stand for thoughts and ideas of a culture and its people, which enhances the intellectual, emotional and social development of the individual by the linguistic transmission of ideas between self and others. It is language in its written or electronic/auditory form which transcends the barriers of space and time, allowing the individual to learn about the past, experience the present beyond the physical confines of his/her own environment and think about and plan for the future. Language, spoken and written, is the medium by which almost all education — particularly schooling — takes place and is the medium by which people relate to each other in almost all of life's activities.

In the foetus, hearing is present at 20 weeks (ie. 4 months before birth). Indeed the sounds which envelop the foetus are at a noise level about which most adults would complain. Neonates and older infants respond to speech and other sounds, demonstrate preferences for different auditory stimuli, and distinguish between speech sounds (Northern & Downs, 1984). So from their earliest days the vast majority of hearing infants are surrounded by sound, almost always within the context of human interaction. Gradually they distinguish sounds which are associated with activities or feelings such as the sounds of the preparation of bottle or spoon feeding, of running water for the bath, of mother's voice meaning security, comfort, playtime or scolding. Gradually the intonations and words take on meaning and the child begins to develop receptive knowledge of language. At the same time the child is experimenting with his/her speech apparatus until, finally, from the very wide range of sounds the infant makes, those which are reinforced as the words of the culture become those which the child continues to use with greater fluency in the syntax common to his/her linguistic environment. A vital component in the development of speech is the child's hearing of his/her own speech in order to monitor its similarity to that which he/she hears from others in his/her environment.

The hearing-impaired infant is immediately disadvantaged in developing the oral language of his/her culture. Depending upon the degree of hearing loss the baby may hear little or even no speech. If the baby does hear speech its sounds may be very distorted and deficient. The two immediate consequences of this are that the child does not seem to understand much of what is said to him/her and speech development after the babbling stage may be delayed or deficient. Interference with the development of language and the disruption of communicative interpersonal interaction are the most significant results of hearing loss in the total development of the child. However, to the vast majority of the population who have only a hazy, if any, knowledge of the distinction between speech and language, it is the differentness of the hearing impaired/deaf person's speech which appears to be the most significant result of hearing impairment.

This chapter deals with hearing loss, its effects and their amelioration through early intervention. Initially, some definitions are proposed. Some components of early intervention for deaf infants and toddlers are described and the delivery of such services in New South Wales are outlined. Some recent research on studies of early infant-mother interactions is considered.

BASIC DEFINITIONS

The generic term **hearing impairment** refers to all types and degrees of hearing loss. The major classifications of hearing impairment are based upon site of lesion, time of onset and degree of loss. Hearing impairment which is located in the outer or middle ear is **conductive**; that which is in the inner ear or the nerve pathways to the brain is **sensory neural**. Hearing loss which occurs before the age of two years (i.e. before the full development of language) is **prelingual**; that which occurs after the age of two years is **postlingual**. Impairment which may distort but does not preclude hearing the sounds of speech (with amplification) is generally classified as **mild**, or **moderate**; that which grossly distorts or prevents hearing the sounds of speech, even with amplification, is classified as **severe or profound**. Sometimes the clinical definitions of degrees of loss can be misleading when applied to particular individuals, especially in the grey area between moderate and severe, and severe and profound losses.

The **functional** descriptors currently used in New South Wales are **hearing impaired** and **deaf**. Hearing impaired people generally have residual hearing which enables them to maintain interpersonal contact with other people through speech, listening and speechreading. Sometimes the term 'hard of hearing' is used to describe these people. **Deaf** people generally have little or no residual hearing to maintain linguistic interpersonal contact with other people through speech, listening or speechreading alone; therefore their preferred mode of communication is likely to be Sign Language or Total Communication.

Modes of Communication. Hearing impaired people usually communicate using one or other of three major methods known as **oral**, **manual** and **total. These methods involve differing combinations of the following modes.**

Listening

Speech

Lipreading (speech reading): using the observed movements of the speaker's lips (and face) to give clues to assist in understanding his/her speech. Only one third of sounds used in speech can be seen on the lips. The lipreader needs a good understanding of language to fill in the gaps where speech sounds are not visible.

Fingerspelling: the 26 letters of the English alphabet each have a discrete position or pattern on the fingers or hands. Each word in the utterance is spelt on the hands and fingers. This mode is akin to **writing**.

Sign: a system of arbitrary signs which may denote words, phrases, ideas.

Signed English is a system in which signs represent the words of English. Such signs may be supplemented by the use of fingerspelling to denote, for example, differences in tense of verbs. In Signed English the grammar and the word order is the same as in spoken English.

Sign language, Australian sign, Auslan: Signs more often represent concepts than discrete words. Sign language has its own structure and grammar which differ from English.

Oral communication refers to the use of listening, speech, and lipreading/speech reading.

Manual communication refers to the use of fingerspelling and/or sign.

Total communication refers to the use of both oral and manual modes of communication plus any other mode such as writing, gesture, mime in whatever combinations and to whatever extent is necessary to convey the message.

EARLY DIAGNOSIS

Theoretically, the earlier intervention commences the greater the likelihood that the child's learning of language will proceed successfully. Early intervention is dependent upon early diagnosis. Despite the advances made in technology and community awareness over the past twenty years and an increasing tendency for aids to be fitted by age 2 years, Upfold (1979) reported that only 50% of children fitted with hearing aids received their aids by age 6.5 years. An instrument for detection of deafness in newborn babies was devised in New South Wales in the 1950's by Walter Parr. It was then the smallest instrument of its kind in the world and therefore the most portable. Although early use of this device resulted in some false positives, it was the economics of employing persons to administer the very simple test to hundreds of babies which prevented its large scale application. The accepted minimum incidence of deafness is 2.0 per thousand live births — rising, of course, in those years when there are rubella epidemics (Upfold, 1979). With such a low rate of return, hospital administrations could not be persuaded to routinely undertake screenings. At present St. Margaret's Hospital in Sydney is the only hospital in New South Wales to carry out screenings of at risk children. Consequently, the onus of detection lies with the parents.

Because of its invisibility and because a child may respond to the vibrations of a loud sound or the visible movement made by someone producing a sound, deafness can be very difficult to detect. Despite increasing awareness among medical practitioners of the need for early detection of deafness, mothers still report being told they are over-anxious when they suspect a hearing loss in their child. Sometimes medical practitioners suggest that the child simply may be developing slowly. To wait until a child has demonstrated a clear speech delay and has become a behaviour problem through not understanding oral commands, directions, explanations and descriptions, means valuable time has been lost in assisting the child's language development and personal-social development. Sometimes a hearing loss may masquerade as intellectual disability because of the child's slow linguistic development, again causing loss of valuable intervention and learning time. Usually it is the presence of at risk factors which lead to early detection of deafness. Such factors are deafness of parents, siblings or close relatives, the mother's exposure to rubella during pregnancy, and low birth weight in relation to term.

Infants with severe or profound deafness are more likely to be diagnosed early than are infants with mild or moderate losses. This latter group will respond differentially to sounds and to speech, thus confusing the issue and making it difficult for observers to notice and even for trained personnel to give definite answers as to degree of loss. These children are likely to be found early only when they are tested because of 'at risk' factors. Often diagnosis may be delayed until school learning failure results in auditory testing.

THE COMPONENTS OF EARLY INTERVENTION

The components of early intervention are medical/surgical, technological and psycho-educational. After detection, the first level of intervention will be **medical** to determine whether there is a medically or surgically correctable cause of the hearing loss. In cases of sensory neural deafness, there is no presently known cure or ameliorative technique. Cochlear implants currently are not used with infants. In cases of conductive loss, medical and surgical treatment may result in cure or reduction of hearing loss. Personnel employed in early intervention services described below liaise with ear, nose and throat specialists as necessary.

The next step in intervention is usually **technological** and involves fitting of the most appropriate hearing aid. In Australia, the National Acoustic Laboratories provide free audiometric testing and fitting of hearing aids for all children to the age of 21 years. It is the paediatric audiologist's job to fit the most appropriate aid to the child. This requires sensitivity of observation, judgement and interpretation of hearing tests. The audiologist then relies on the care-giver's and teacher's reports of the child's auditory behaviour, speech reception, language development and social behaviours to evaluate the appropriateness of the fitted aid. Each of the early intervention services described later, maintains close contact with the paediatric audiologists serving their children.

In many cases of hearing impairment, amplification of sound enables the listener to hear speech, but if the organ of Corti or the auditory nerve have been so damaged that they cannot respond to sound, the hearing aid cannot help. For many deaf people, the major benefit of a hearing aid is to enable them to hear the duration and the stress patterns of speech. Any person fitted with a hearing aid needs to be taught how to gain the maximum auditory advantage from it. Thus it is important that the young child in an early intervention program be taught the skills of listening and to distinguish, as much as possible, the time and intensity cues of speech which are transmitted through the hearing aid. For some deaf children, this is a very difficult task indeed. It is of utmost importance to understand that a hearing aid does not restore hearing; it is mainly an amplification system. Some children have no observable response to amplified speech. These children are fitted with vibro-tactile aids which allow them to feel some of the different vibratory sensations produced by amplified speech and therefore to assist them both in interpreting speech and in producing it.

For more extensive and specific information on hearing aids the reader is referred to the excellent publications by the National Acoustic Laboratories whose phone numbers will be found in the Commonwealth listings of the Australian phone directories.

The two **psycho-educational** areas of most vital concern in the early development of young deaf children have always been **parental response to the hearing-impaired child** and the **development of language** by the child. This has been so since the first early education and parent guidance programs were introduced overseas at the end of the 19th Century until the present where the same concerns were expressed at the 1986 National Language Workshop in Melbourne. Those participants who had been in the field for upwards of 25 years noted that while research was continuing into the language development of deaf infants and into mother-child interactions, there was also a resurgence of interest in the initial and continuing adjustments required by the presence of a deaf child within the family. A panel of hearing mothers expressed similar concerns to those reported in an earlier study of mothers of young deaf children in New South Wales (Rumsey, 1977), namely, the difficulties experienced by parents of children with any disability as they deal with initial diagnosis and the grief process, and those difficulties specific to adapting to a child who hears little or nothing and who needs specific teaching not only to learn language and speech, but also to develop both interpersonal relationships and daily living skills which are usually understood through the oral linguistic communications which accompany them. Enhancement of language learning by hearing-impaired children has varied in the last one hundred years from highly structured to natural language approaches. The current emphasis is on a natural conversational approach, no matter which mode of communication is favoured.

Compared with the situation of twenty years ago, there certainly are more services available to support families with hearing-impaired children, but whether these have actually kept pace with increases in population is debatable. Other increases have been in the numbers of families with multi-disabled children and the numbers of parents whose first language is not English. The proportion of hearing-impaired children from homes where English is not usually spoken is very similar to the proportion of the Australian population whose first language is not English (Rumsey, 1984).

THE ROLE OF THE TEACHER IN THE EARLY INTERVENTION PROGRAM

The role of the teacher in the early intervention program for a hearing-impaired child will have different emphases depending upon the experience and training of the teacher and the type of early intervention program. As this book is a general one on early intervention, the major emphasis here will be on the role of the teacher who is trained in the principles and practices of early intervention but without specific training in the area of hearing impairment. All of the major principles and practices of early intervention will apply with the following additions.

In New South Wales it is likely that the hearing impaired child in what may be termed a Department of Education 'general' early intervention program will have a mild to moderate loss in conjunction with another handicap which may be more severe. Such a child should, and generally will have the services of an itinerant teacher who will be skilled in understanding the development and teaching of auditory skills, language and speech. However, in locations outside the major cities, that person may not always be trained in early intervention principles and practices. Therefore, it will be the responsibility of the program teacher and the itinerant teacher to work together to provide the best possible early intervention program for the child. At times the itinerant teacher of deaf children may act as a consultant to the program teacher, at other times as a model in demonstrating techniques. On occasions he/she may withdraw the hearing-impaired child for specific auditory, language or speech developmental training and at other times may provide assistance for a group of language disordered/delayed children including the hearing impaired child. The itinerant teacher will act as a resource for the program teacher for information and referrals and may be the person who consults with the paediatric audiologist on the auditory status of the child. Sometimes the program teacher will consult directly with the paediatric audiologist. To do this intelligently, the program teacher will need to develop a basic knowledge of audiology and good skills in observation and record keeping of the child's auditory, language and speech development. Both the program teacher and the itinerant teacher will consult with the child's caregivers so that ongoing support is provided and so that the language, speech and auditory skills being taught are relevant and generalise to and from the home situation.

It will be incumbent upon the program teacher to develop the appropriate techniques for communicating with hearing-impaired children. This will require adaptations in relation to positioning so that the child can both clearly see and hear the speaker as far as possible. Such adaptations will necessitate the teacher's constant awareness of the source and levels of light, which should be behind the child and falling on the hearing person's face; the intensity level of environmental sound which will interfere with the child's auditory reception; and the speaker's necessity to be as close as possible to the microphone of the child's hearing aid. Where a child is fitted with an FM wireless aid, the teacher will be required to wear the accompanying microphone. The teacher will need to monitor his/her own speech to ensure clear articulation and appropriate chunking of language to give the child normal linguistic models and to use appropriate language levels for the child. Where a manual supplement such as Signed English or Makaton (in the case of multiply handicapped children) is recommended, the teacher must become fluent in its usage. The use of manual communication will not assist the development of a child's language if the user does not competently and fluently sign at a level superior to that of the child. Where a child has a usable amount of hearing for speech, incompetent signing which impedes the natural rhythm of the teacher's spoken language will be a hindrance to the child's development of auditory language and speech.

In early intervention settings designed specifically for hearing-impaired children the program teacher's role will have different emphases. In New South Wales, with only rare exceptions, all early interventionists in such programs are trained teachers of hearing-impaired children. Some have specific early intervention or early childhood training, others may have previously taught children in the 5-8 years age range. In these programs the hearing impairment teacher is primarily responsible for the delivery of the program to the child and his/her caregiver. Great emphasis is placed on the role of the primary caregiver in the early listening, language and speech development of the child. Consequently the teacher works in very close cooperation with the caregiver to determine the content of the specific learning situations, to monitor the child's progress and to develop the caregiver's understanding and skills in fostering the child's development, specifically in audition, language and speech. At the same time the caregiver's role must remain primarily that of caregiver, not teacher. The child's whole development and the caregiver/child relationship must be enhanced, not reduced or destroyed by the additional requirements or impositions of the disability.

SERVICE DELIVERY IN NEW SOUTH WALES

The description of the delivery of early intervention services will focus on New South Wales as the State provides examples of most, if not all, types of services which operate in the remaining states of Australia.

Through **Hearing Centres** located throughout the metropolitan area and in large country towns, the National Acoustic Laboratory provides paediatric audiology services for diagnosis of hearing loss, and fitting and maintenance of hearing aids for all children to age 21 years. After diagnosis it is the responsibility of the caregivers to choose which of the support services they wish to avail themselves of. This decision is made in the light of information provided by the various services, the desires the caregivers have for the child and, it must be admitted, the pressures exerted by those people who think they know what is best for that particular child.

The **New South Wales Department of Education** provides centre-based early intervention services from diagnosis through its specialist itinerant teachers of hearing-impaired children located at Hearing Centres in the city and in large country centres. Geographically isolated hearing-impaired children are seen at their nearest public school by the itinerant support teacher (hearing). The child and his/her caregivers attend the centre generally on a one hour per week basis. A number of **public hospitals** such as the Royal Alexandra Hospital for Children provide a similar service through audiologists or speech pathologists in their Audiology or Hearing Clinics. From age three years, the New South Wales Department of Education enrols hearing-impaired children in preschool programs at the two special schools for deaf children in Sydney, — North Rocks Central School for Deaf Children and Farrar School for Deaf Children, Croydon Park — and in special nursery classes located throughout the metropolitan area and in country centres as the need arises. Children attend these classes for the regular school hours, taxi transport to and from school being provided at government expense. Where family support other than early intervention teaching techniques is required, teachers must refer the parents to the school counsellor/psychologist. The child's progress is monitored by the itinerant teacher, the more senior visiting teacher, the local specialist school counsellor and the child's caregivers.

The Catholic Centre for Hearing Impaired Children, at Strathfield, Sydney and in Newcastle aims to help the hearing-impaired child reach his/her full potential and to provide support for the child's family. This is achieved by providing for each child's individual needs taking into account his/her hearing loss and cultural background. Specifically, the child is assisted to develop language using whatever mode of communication the family and the centre staff deem most appropriate. Children of all cultural backgrounds, degrees of hearing loss, whether of hearing or deaf families and all those for whom there is no other more appropriate service are accepted into the program. Service delivery consists of home visits, two or three times weekly, to optimise the development of situational family language and involve as many family members as possible; tutoring and/or playgroup sessions at the centre; parent support and education meetings on a regular basis, and visits to local non-Department of Education preschools where children are integrated to support the teachers and assist in the management of the deaf child. The staff aim for an unpressured, flexible program which accommodates the different needs of families and individuals.

The Shepherd Centre at Darlington, Sydney, is an independent, government-subsidised intensive program for hearing-impaired children and their parents. Its declared aim is preparation of the child to enter regular kindergarten using oral methods of communication. Consequently, it is an entirely oral program requiring intensive involvement on the part of the parent or caregivers. Service delivery is both home- and centre-based. Home-based delivery is provided for infants until they are eligible for enrolment in kindergarten, usually at age 3 years. Whichever service the family is receiving, at least one of the child's caregivers is required to attend the centre one day per week, to teach the child under the direction of the trained teacher, to demonstrate techniques to other mothers/caregivers, and to confer with the child's teacher, the social worker and other caregivers on relevant matters. Attendance is also mandatory at fortnightly evening meetings designed to educate parents/caregivers and family members in relevant aspects of hearing impairment, family management and education of hearing-impaired children.

Once the child is old enough for enrolment in a non-Education Department preschool program, the Shepherd Centre provides itinerant teacher support for the child. In some cases, the Shepherd Centre has used caravans based at a kindergarten in a country town or outlying suburb to cater for children not living within reasonable travelling distance of the centre.

A feature of the Shepherd Centre program is the correspondence course which it offers to country, interstate and overseas parents. This is supplemented by an annual intensive workshop at the Centre for which isolated parents are given financial assistance to enable their attendance. If any child does not appear to be benefiting from the Shepherd Centre's purely oral program, the parents are referred to other early intervention services for deaf children.

St. Gabriel's Family Support Centre, at Castle Hill, has the overall objective of enabling the hearing impaired child to 'understand and be understood in spoken English'. The centre offers an oral/aural program supplemented by cued speech when the combination of residual hearing and speech reading does not lead to error free reception and subsequent development of spoken language. The program acknowledges the parents as the primary educators who are supported by a teacher/clinician and a social worker who function in close liaison. The services offered are individual weekly sessions and monthly home visits for parent/s and child with a trained teacher/clinician; monthly home visits and monthly mothers' meetings by the social worker; regular weekend workshops for parents, evening workshops for fathers and special workshops for grandparents; ongoing liaison with paediatric audiologists, and with paediatric and ear, nose and throat specialists as required. All program services are free and available to preschool aged hearing-impaired children of any religious denomination.

CONTENT OF EARLY INTERVENTION PROGRAMS

In all the programs, the major emphasis is on assisting the caregiver to maximise the child's development of receptive and expressive language, to utilise fully the child's residual hearing through the optimal use of his/her hearing aid for the development of auditory skills, and to enhance speech development. Teacher and caregiver together devise an individualised program for each child within a generally accepted framework. Education of the parents as to the present and future implications of the disability, its amelioration through education and, if appropriate, medical/surgical techniques, as well as contact with other parents is provided through both formal and informal means. The development of a warm relationship between the child and the caregivers is encouraged through the facilitation of communication with the hearing-impaired child and management suggestions are made where necessary and appropriate. To varying degrees, parents are supported in working through their reactions to the knowledge that their child is hearing-impaired and the implications of that disability. Where serious problems of adjustment arise, the services of psychologists are provided through referral.

The major differences between each of the services are the mode of communication which is emphasised and whether service delivery is home- or centre-based. The Shepherd Centre uses oral communication methods; St. Gabriels, the oral/aural mode supported by cued speech, and total communication according to parental preference; and the Catholic Centres and the State Department system oral or total communication as requested by parents/caregivers.

In one sense, the Shepherd Centre and St. Gabriels operate at an advantage. They have limited the services they provide to one communication mode, with children who do not respond to that mode being referred elsewhere. Consequently, all their efforts are concentrated into a single provision by personnel and family who are firmly committed to that approach. Additionally, they require greater commitment on the part of caregivers in terms of work with the child, attendance at the centre and involvement in fund-raising activities. This implies that, in general, more of the children enrolled in these programs have the maximum support of their caregivers in the quest towards the achievement of the best language and speech of which the child is capable.

The State system and the Catholic Centre provide the range of communication modes and do not make parental commitment and ability to carry out the centre's program at home a requirement of entry. Consequently the degree of family support for the hearing-impaired child varies greatly. Where mode of communication is concerned, the wishes of the parent/s are paramount. Therefore a teacher occasionally has to use a mode of communication which he/she does not feel is the most advantageous to the child. Of course, the advantage of these systems is that when parents agree that a particular mode is not the most suitable one for the child the transition to another mode can be made without the upheaval of removal to an entirely new service.

MULTI-HANDICAPPED CHILDREN

The major early intervention service for severely multi-handicapped hearing-impaired children is provided by the Royal N.S.W. Institute for Deaf and Blind Children at North Rocks. A multidisciplinary team approach is used to deliver home-based services appropriate to each child. The wide geographical area over which their clients are spread is a major problem for service delivery.

Hearing-impaired children with mild additional handicaps are served by the N.S.W. Department of Education and sometimes by the other services. These children are particularly challenging as the multidisciplinary approach must be broadened to take account of their additional disabilities. Generally if hearing impairment is deemed the greater handicap, the teacher of hearing-impaired children will take the role of primary service deliverer or of consultant. In each case he or she has to take into account sometimes conflicting demands on time and program emphasis for the child. Highly developed interpersonal communication skills are therefore an additional requirement for the teacher in this situation.

EARLY INTERVENTION RESEARCH

The language development of the very young deaf child has been the focus of some recently published Australian studies. For example, Mohay's longitudinal study of three deaf children aged 13-21 months who were exposed only to oral/aural communication revealed that the children developed 'extremely meagre' gestural and spoken lexicons and a very simply structured communication system. They were, however, 'able to express the same semantic relationships as hearing children of a similar stage of language development'

(Mohay 1980, p.344) and, in spite of the absence of a mature language model, produced a complete communication system which had many language-like features.

A major focus in Australian research has been the modifications hearing mothers make to their speech when they talk to their deaf infants/young children (Cross, Kirkman, Nienhuys, Horsborough & Johnson-Morris, 1981; Cross, Nienhuys, & Morris, 1980; Mohay, 1986; Nienhuys, Cross & Horsburgh, 1984; Nienhuys & Tikotin, 1983). Results indicate that the mothers of deaf children reduce the complexity of their speech and have lower expectations of their child's response than the mothers of hearing children. As all mothers used only oral/aural communication with their deaf infants/young children, and given that severe-profound deafness dramatically interferes with oral communication between individuals, such results would not be unexpected. Although simplified maternal speech has been thought to promote child language development at certain ages, most of the researchers found that the complexity of maternal speech to young deaf children did not change at different age levels. Indeed, Nienhuys et al. (1984) reported that mother's speech to deaf five-year-olds was very similar to that used with hearing infants. Consequently, Nienhuys et al. (1983, 1984) suggest that their children's deafness causes such extreme adjustments in mothers' speech that the linguistic environment they provide for their deaf children hinders rather than helps the child's communication development. These findings which accord with those of overseas research, and the researchers' conclusions further emphasise the devastating effect which early severe-profound deafness has upon oral interpersonal communication and by implication upon the socio-personal development of the deaf child.

Another aspect of maternal-deaf child interaction was studied by Hyde, Elias and Power (1981). Their sample of twelve mother-deaf child dyads did include three congenitally hearing-impaired mothers, two of whom communicated with their children by manual methods, and one by oral means only. The researchers concluded that mothers of deaf children were more controlling, both verbally and non-verbally, in their interactions with their deaf children than were mothers of hearing children. They also found that the grammatical form of the mothers' speech did not vary with the age of the deaf children. Again, the suggestion was made that these adaptations result from the communication difficulties imposed by early childhood deafness. The questions which arise from these research findings include:

1. Are such adjustments necessary features of mother-deaf child interactions?
2. Do they result from the mothers' perceptions of the limiting effects of deafness?
3. Do they result from long established early intervention practices which mothers are taught in clinics, preschools, etc?
4. Are they appropriate in terms of the child's total development?
5. Should or should not, or even may, they realistically be changed through alternative intervention strategies?

Another avenue of current interest both in Australia and in the United Kingdom is that of comparison between the interactions of deaf mothers with their deaf children, hearing mothers with their hearing children and hearing mothers with their deaf children (National Language Workship, 1986). After analysing a small sample of earlier data, Nienhuys and Tikotin (1985) reported that deaf infants of hearing mothers 'seem less likely . . . to engage in meaningful social and play interactions with their mothers' (p.12). Research literature reviewed by Quigley and Kretschmer (1982) supports informal observations by teachers, psychologists and welfare workers that deaf parents establish better communication earlier with their young deaf children than do hearing parents. Such findings, together with the relatively recent acceptance of Sign Language and Signed English as opposed to insistence upon speech and speechreading as acceptable modes of communication between deaf and hearing people, has led to the research interest in the communicative interactions between deaf mothers and deaf infants as a possible means of learning how to enhance the communicative interaction of hearing mothers with deaf children. This research is still in its beginning stages. It is too soon to draw conclusions which can be translated into practices or techniques for early intervention programs.

Some overseas research has attempted to study the efficacy of early intervention programs for hearing impaired children (Moores, 1982). However, such research is scarce because of methodological difficulties. As deafness is a low incidence handicap the numbers of subjects fulfilling requirements for comparisons are few; most programs are based on communication ideologies; and withholding intervention for purposes of comparison of intervention and non-intervention results is unethical because it is seen as denying support which is believed to be beneficial. Comparisons of different interventions are not yet possible or appropriate.

CONCLUSION

This chapter has provided an outline of the major effects of early hearing-impairment upon infant/young child development, and the processes by which early interventionists endeavour to ameliorate such effects. During the past 100 years various approaches and philosophies have been used. In the last two decades, hearing aid technology has advanced rapidly, early intervention services have become more widespread and knowledge of caregiver — child communicative interaction and child psycho-linguistic development has increased. Nevertheless the challenge remains of providing the best possible developmental environment and support to both infant/child and the family.

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Chapter 13

INTERVENTION PROGRAMS FOR VISUALLY IMPAIRED CHILDREN

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This report is the result of extensive discussion by staff in the Early Childhood Development Department of the Royal Victorian Institute for the Blind. It draws together the results of long deliberations by members of the Department, who work within the framework presented here with a commitment that stems from participation, as a team, in its formulation.

The report is organised into three sections. The first presents a statement of basic underlying values and principles. The second outlines the range of early intervention services offered by the Institute and provides a further insight into the philosophical framework within which the Early Childhood Development Department functions.

INTRODUCTION

The Royal Victorian Institute for the Blind provides services to visually impaired children, regardless of other handicap, from birth to 16 years, and counselling services to the families of these children, particularly in the early years. Some of the children are multiply impaired, while a number have a history of prematurity and low birth weight. Some low birth weight children survive with a significant visual impairment which may be one of several other impairments; visual impairment in premature babies through retrolental fibroplasia or other damage due to anoexia, represents a significant proportion of our preschool population.

There are several major obstacles which must be overcome if visually-impaired infants are to realise their fullest potential:

1. Interrupted Bonding. Most people are now aware of the importance of the mother-child relationship to the emotional security of the child. Research has demonstrated that normal infants can discriminate their mothers from strangers at one month of age and preferentially attend to their mothers by three months, an age at which many premature babies still require hospitalisation. Even when efforts are made to minimise the number of caregivers, institutional care, including hospital care, generally necessitates well over six people handling each baby. This is the number considered to be the maximum that a young baby can tolerate and still establish trust. (In one known instance, up to 60 staff had an involvement with one child over a period of a week).

The impact of interruptions to a mother's bonding to her premature hospitalised baby are clear. A group of such mothers sharing their feelings reported that they felt 'cheated of the birth experience' and acknowledged feelings that followed of 'this is not my baby'. For most mother-infant pairs, bonding can, and usually does, occur. However the significance of eye contact between mother and child to cement the bonding process is not well understood, and it is the experience of Institute staff that blind and multiply-handicapped babies have enormous difficulty in establishing maternal recognition and, through this relationship, the sense of ego and self worth which is essential to further development. So a major hurdle to the quality of life for visually-impaired infants is the difficulty, in some cases insurmountable, that many have in establishing relationships, even when the mother herself has bonded successfully to the infant.

2. Learning to Touch. Without sight, the baby must use touch as the sense which will integrate his experiences. Wanting to know and understand the world outside one's own body is the single most important indicator for successful learning. But these babies' experience of touching is frequently limited and is often associated with discomfort or pain. As a result, they become tactile defensive and shrink from the world around to the security of their own inner world and to self stimulatory activities (eye poking, rocking and light gazing are some well known blindisms).

The road to learning, then, requires consistent and massive direct input from a loving adult, to introduce the outside world and to extend experiences, often in the face of loud and sustained opposition by the child. If it is the mother who provides such effort, she does so at considerable cost to her own and her families' resources, and with no guarantee of success. It is hard to consistently interact with a child who does not want to be touched, gives few smiles, eye contact or other signs of response and understanding. If cerebral palsy is also present the task for the mother is even harder. The cerebral palsy blind child's tentative efforts to explore and make meaning of the world will actually be blocked, since there are restrictions in the child's ability to translate intentions to grasp and touch into actions, and, without motivation or success, the child may soon stop trying.

The learning pathways for a blind child differ from his or her sighted peers. About 80% of learning occurs visually but the blind child must interpret sound, smell, touch and taste without the reinforcement offered by taking another look to check out the information received. Experiences are limited and largely dependent on introduction and interpretation by others. It is not surprising, then, that people often find it hard to recognise what a blind child comprehends, and it is also difficult for the child to show others what he or she knows and understands. As a result the blind child is undervalued, with skills unrealised — an unacceptable price for any child to pay. The task before parents is therefore a formidable one. Blind children with no additional handicaps can and do achieve high academic and personal goals but it takes longer to learn without sight and requires vast human and material resources.

There are several observable times in the child's development when particular difficulties must be faced. For example, within our culture, when the babyhood period is over, around 2 years, a second baby is often born. The parents are psychologically ready for the total dependency of babyhood to progress to the next stage, involving a mastering of skills that will allow the parents to gradually disengage. The realisation that this stage may not be reached with a blind baby, confronts the parents again with the complications of handicap within their family. At 5 years or thereabouts, when other children commence school and parenting becomes a 3.30 pm to 9.00 am role weekdays, these parents again look forward to a lessening of dependency both for their child and for themselves. The dilemma remains that the parents' need for lesser input is incompatible with the child's continuing needs, for, if his or her waking hours are not filled with stimulation, the blind child will withdraw and self stimulate.

At adolescence the parents are confronted with the enormity of their continuing task. The blind and multiply handicapped blind baby and small child who may be tolerated within the community presents as a new problem with the coming of puberty (secondary sex characteristics in people whose mental ability and social skills are severely delayed may be seen as an affront to the sensibilities of normal people) and caring takes on a new dimension. It is a time when a resurgence of the feelings parents had at the birth of the child may seem intolerable, with the result that many multi-handicapped children maintained within a loving family circle to adolescence are then placed in communal care. By around 20 years of age, parents generally expect to see their children leave home to establish careers, and so their day to day interaction ceases, although not their loving and caring. The parents of the multiply handicapped blind young adult realise that this real step may never be taken. The slow and painstaking progress towards fullest potential must continue within a planned educational framework.

Often, in time, the community will be called on to provide residential care — a dismal prospect for most parents to contemplate, considering the community lack of interest, understanding and support that will have been their common experience. It should be the community's responsibility to ask the parents what help they need now and in the future, and to ensure that this is provided. Relief from the caring role must be offered without prejudice if parents are unable to maintain their support. The price will be considerable in both financial and human terms but there is no choice: the die is cast, with the survival of these tiny babies who are significantly handicapped.

A. UNDERLYING PRINCIPLES

Statement of values

The Early Childhood Development Department (ECDD) of the Royal Victorian Institute for the Blind adopts a fundamental premise that children's programs are established by designing educational objectives based on the following:

a. the child's developmental status as determined by initial and ongoing assessments.

b. normal child development — normal development follows an established pattern of skill acquisition and where practicable, this pattern provides the basis for programming.

c. the impact of disability on normal development.

d. the individual child's interests and preferences.

e. consideration of the families expressed needs.

f. the perceived future educational needs of the child.

g. medical considerations.

A number of other initial features of the program are acknowledged by the staff. These include:

- Each child will have regular systematic testing of visual response and functioning, and be provided with an appropriate program of visual stimulation or training. 'For visually impaired children, vision is not an automatically learned process. Unless a well planned program of visual stimulation is provided, visually impaired children will not reach their optimum levels of visual functioning.'

- Sensory experiences should be provided to stimulate all sensory modalities: tactile, olfactory, visual, auditory, gustatory and kinaesthetic. These experiences should then be developed perceptually and cognitively to maximise the child's interactive ability with the environment.
- Reference to a multi disciplinary team is basic to establishing a diagnosis and prescribing an adequate learning profile for individual children. This would recognise the child's medical condition including an assessment of their visual impairment.
- Continuous assessment, both of the program and the child, is essential to program implementation.
- It is also recognised that development will be maximised by consistent management. Provision is made to assist in establishing consistent management between the home and school environments and all parents are encouraged to be participants in their child's program.
- Parents are the principal caregivers of each child, and program effectiveness will be maximised if parents are involved in the program, and if parents needs are being met through the program. Parents are invited to participate in Program Planning Meetings and Reviews.
- Parents are provided with knowledge of the program, information on services, and information regarding their child's visual impairment.
- The ECDD recognises the uniqueness of each individual, and attempts to provide the optimal learning environment for each visually impaired child.

Developing programs for visually impaired children

Young, visually impaired children have difficulty in achieving normal developmental patterns because of the impact of the impairment upon their learning profiles. While not proposing a deficit model for intervention, the following areas of difficulty are considered to be significant factors in curriculum design for visually impaired children.

1. **Development of Human Attachments**
   As noted earlier, early attachments to parents may be adversely affected by prolonged hospitalisation and subsequent separation from parents; reduced responsiveness on the part of the parents, either as a result of rejection of the handicap, or an inability to identify with the needs of the visually impaired child; and lack of eye contact between the child and the mother, and significant others. Difficulty in primary attachments may lead to subsequent difficulties in secondary attachments and the poor development of exploratory behaviour.
2. **Self Concept/Body Image**
   Self concept, in a physical and psychological sense, may be negatively influenced. To perceive the self as an individual, separate and to some degree independent, requires confirmation from all the senses. Therefore the visually impaired child may be delayed in differentiating between self and non-self. Body image may be incomplete or distorted, as the child lacks an overall visual reference. There is no single sense that can take over the function of vision in replicating body image.
3. **Experiential and Sensory Deprivation**
   In the absence of visual lures, the visually impaired child's experience of the environment is restricted. This in turn inhibits the child's motivation to explore and interact with his or her environment. Further, opportunities for incidental imitative learning are limited. In addition, because the visually impaired child has limited channels of access to understanding and interpreting the environment, he or she

receives less quantity and poorer quality of stimulation. This experiential deprivation leads to inadequate development in, and poor utilisation of, sensory modalities.

4. **Adaptive Responses and Prehension and Locomotor Skills**
   Early adaptive responses may be restricted as the child's ability both to influence the environment, and to recognise his or her potential to influence the environment, is limited. Early prehension skills are also hindered, as the motivation to grasp distant objects is absent or restricted to those with sound cues or to those accidentally encountered. This limits the child's ability to explore. Early locomotion skills may be similarly delayed.
5. **Communication**
   The visually impaired child may be restricted in the cognitive motivational and interactional pre-requisites for normal communication development. He may take longer to negotiate stages of language development and consequently may exhibit significant communication delay.

In view of the areas of difficulty identified above that have been shown to affect the development of young, visually impaired children, the specific aims of the programs provided by the ECDD can be specified in relation to **learner outcomes**, in the following terms:

a. To develop self esteem.
b. To encourage curiosity and exploration.
c. To develop a positive attitude towards learning.
d. To promote the development of communication skills.
e. To develop the use of residual vision.
f. To develop skills to maximise the child's participation in the community.
g. To promote the development of sensory integration.

In addition, three specific aims have been identified in relation to the **provision of services:**

a. To provide flexibility of service to facilitate the most appropriate level of integration.
b. To encourage the parents to be participants in the children's program.
c. To provide continuity of management between school, residential setting and home.

The **programs** provided by the ECDD is based upon an assessment/intervention model. It is assumed that specific behaviours can be described in a developmental sequence which is not norm or age referenced, but which attempts to establish individual learning profiles. However, such profiles may be characterised by disparities within and between developmental areas, with development occurring in an idiosyncratic pattern that is not reflective of expected development sequences. Thus, low functioning in one area does not imply that a child is low functioning in all areas. The program is directed at developing both the strengths and weaknesses exhibited in each child's learning profile.

The essential precursor to behaviour management and to all programs for the visually impaired child is the establishment and development of: emotional bonding, sensory stimulation and sensory integration. These are heirarchical and are considered to be fundamental to all aspects of the program and elementary components of all curriculum areas. Bonding is an essential to compensate, where necessary, for inadequate development of early attachments and to develop trust of the people with whom the child is to interact. The teacher must attempt to create a secure environment for the child, in which experiences are predictable, simple and familiar. The establishment of meaningful routines, and repetition of experiences assist in the development of a secure environment. A co-action strategy is commonly adopted to assist the child to reach out, and the number of adults with whom the child is expected to interact is restricted, to foster the development of meaningful relationships.

Stimulation must also be provided in all the sensory modalities with an emphasis on developing selective rather than diffused responses. Careful monitoring of sensory input is essential to ensure that the child is neither under or over stimulated as both are counter productive to appropriate responses. Sensory integration training is used to enhance the brain's ability to learn the processes involved in accomplishing the skills of receiving, perceiving, remembering and motor planning; (ie. adapting responses to life situations that are appropriate). This helps the child to process sensory information more effectively and provides a greater repertoire of responses. Finally, a child with residual vision requires regular systematic testing of visual response, and the provision of a program of visual stimulation or training.

B. SERVICES

The Early Childhood Development Department provides a special education program for all children (0-6 years) who have, or are reasonably suspected of having, a visual impairment, regardless of other impairments. Admission to any program is dependent on the Enrolment Panel's assessment that the Institute has the staff and resources to responsibly manage the child's and its family's on-going education, social and emotional needs. Visual deprivation combined with lack of early stimulation results in the most severe lags in development, and conversely, additional early stimulation seems to result in increased visual attentiveness. It is therefore essential that every child with a visual impairment receives stimulation during the first vital months and years.

Home Advisory Service

This early intervention service was established in 1978 in its present form. It is partially government funded through the Commonwealth Schools Commission. It provides an early intervention service to visually impaired children from birth to 3.5 years of age and accepts referral from the time that a visual impairment is first diagnosed. Support from the home adviser for the parents in these early stressful days can lead to an understanding of their child's condition, and an awareness of their future role in his or her education as the best care-givers. Home visiting provides access to a service when it is impractical for families to visit a central location. In addition, such young children need the security of familiar surroundings to ensure optimum conditions for learning, and teaching techniques and experiences can be personalised to take account of the family situation and environment. Regular and frequent contact is maintained as home advisers visit the homes of these very young children throughout Victoria weekly to every six weeks, depending on need.

The service has a dual role of counselling and educating. The **counselling** aspect progresses from an active listening role to a definition of needs and a constructive plan of action to meet those needs. The home adviser helps guide the family through any complex feelings such as disappointment, helplessness, confusion and sadness over the 'whole' child who will never be, to an acceptance of the 'impaired' child who is a family member. The **educational** aspect promotes an understanding of the anticipated developmental deviations or lags seen in visually impaired children, and shares information and guidance which will lead to the child's adaptive solutions. If other impairments are present, the impact of the **combination** of all impairments must be fully realised for appropriate planning. This necessitates consultancy between educators, medical and para-medical staff and parents. It is crucial that early intervention is based on accurate and detailed information of each child's visual functioning and the implications of such visual functioning in understanding the child's environmental perceptions and education needs.

The Pre-School Visiting Teacher

It is the policy of R.V.I.B. school to maintain the visually impaired child within his or her own home, community, and local educational facility whenever possible, supporting the parents as the child's best caregivers. For responsible management, such a scheme requires careful planning and implementation. The role of the pre-school visiting teacher to visually impaired pre-school children has developed in line with this policy. This position attracts Department of Community Services subsidy. The pre-school visiting teacher is required to have formal and Health Commission approved Early Childhood Development qualifications,to have counselling skills, and to gain extensive knowledge of children with visual impairment. He or she is required to work within the Institute's pre-school, the other educational facility and the child's home, as appropriate, and is responsible for ensuring that the visually impaired child receives a co-ordinated and appropriate educational program irrespective of siting. The duties of the teacher, therefore, include the following:

a. Preparation of the appropriate educational facility:
    i) Liaise with the Department of Community Services, Advisers, Directors and Principals of such facilities prior to placement.
    ii) Provide personnel with appropriate information on the child's visual impairment.
    iii) Provide specialised materials (eg. 'kinder kit') to extend knowledge of visual impairment.
    iv) Where appropriate, discuss preparation of other children with parents.

b. Work with the visually impaired child within the other facility or work with other children, freeing the other teacher to work with the child.

c. Provide or advise on specialised or adapted material to the other centre or the home.

d. Supervise other R.V.I.B. staff such as a Child Care Worker. Attend the other centre with the visually impaired child, to ensure the child's best progress.

e. Liaise between the parents, the other centre and R.V.I.B. staff who may be working with the visually impaired child at other times throughout the week, establishing the agreed lines of communication. Arrange for regular contact between all staffs actively involved in working with the visually impaired child, ie. teachers, Orientation and Mobility Instructors, Child Care Workers, etc., through meetings, telephone contact, written reports or visits between staffs to each other's centre.

f. Liaise with other supporting agencies (eg. medical, educational and community) involved in care of the child, and disseminate relevant information throughout within the bounds of professional ethics.

g. In conjunction with staff of the other Centre, establish and maintain contact with the parents of other children, responding to their needs through provision of such facilities as may increase their knowledge and acceptance of integration.

h. Establish and maintain an adequate case record of the visually impaired child. Co-ordinate regular reviews and provide reports to relevant agencies.

i. Arrange for a case study to be presented to the R.V.I.B. panel to establish future management and placement and then to co-ordinate the interested agencies involved in future placement, eg. school visiting teacher, school staff or Education Department Counselling, Guidance and Clinical Services.

Consultancy Service

For children whose major impairment indicated an educational placement at another Centre, R.V.I.B. provides a consultancy service to staff at these Centres on visual stimulation programs. A visiting teacher attends the Centre to evaluate the child's level of visual performance and advise on future objectives.

Parent Program

Parents both need and benefit from contacts with each other to share the experiences, joys and difficulties of rearing an impaired child. The parent room is available at all times for parents to meet informally without staff. Monthly evening meetings are arranged by the Parents Association, with the agenda suggested by parents and including lectures, discussion groups, films and workshops. Small parent support groups have formed, particularly in country areas, and in some cases identified with a particular eye condition such as Retrolental Fibroplasia and Albinism. Staff support is available. In addition, parents are actively involved in programs, and are included in their child's education for consistency of handling.

On-Site Facilities

For some children, the usual local pre-school ratio of 2 staff members to 25 children may be inadequate for their best development. When geographically possible, such children may attend R.V.I.B. pre-school where a range of services is available. These services may include:

a. **Toddlers' Group** Toddlers and their parents attend for 1 or 2 sessions each week to work with trained teachers and caregivers. The parents observe their child's progress, learn techniques for expanding their child's environmental experiences and share time together socially away from the children for short periods of time.

b. **Pre-School Group** Some pre-school children, mainly comprising those who live close enough to R.V.I.B., attend for up to 4 days weekly for a pre-school program. In the past, their readiness for pre-school experience with sighted children has indicated the need for an integrated program on site, but since 1984, the integration experience has been managed in local pre-school centres. The integration project has served as a desirable model for other disabilities, and plans are currently underway for a more general evaluation appreciation of this model.

Off-site Programs — The Bennettswood Pilot Project

The Department of Community Services of Victoria actively promotes the integration of children with special needs into community settings. In providing an excellent standard of pre-school education for all children, the Pre-School Division has acknowledged that children with major disabilities may need special teaching. In 1984 a pilot project was introduced for the integration of three legally blind children into a community pre-school (Bennettswood Preschool). This project was conducted in conjunction with the Royal Victorian Institute for the Blind, Early Childhood Development Department.

Careful consideration was given to the selection and preparation of the children chosen for this project.

Simone is totally blind and integrates her sensory input through touch, using sound as an important information source.

Jordina has light perception only and needs many 'hands on' experiences to understand her environment.

Rachel has very limited vision in dull conditions but is almost totally blind in bright light. She must learn to use her residual vision when she can, and compensate through heightened sensory awareness at other times.

The developmental level of each child was an important factor in their selection. Areas considered were:

a. appropriate level of self help skills
b. ability to communicate needs
c. ability to interact socially
d. mobility skills
e. gross motor skills.

Consultation between R.V.I.B. and Bennettswood staff in 1983 produced an integration schedule which included visits to R.V.I.B. by Bennettswood staff to observe and meet the children, and to gather information on visual impairment; visits to Bennettswood by children; and mobility instruction in the Bennettswood Pre-school. Flexibility of service was important if the individual needs of the children were to be met, and they could move through the integration schedule at their own rate. So the children were gradually introduced to the full program of four half-days at the Bennettswood Pre-school, accompanied by their R.V.I.B. teacher, and four half-days at R.V.I.B. The importance of the time at R.V.I.B. is justified on the basis that the young, visually impaired child receives less quantity and poorer quality of sensory stimulation and learning experiences. Therefore, he or she requires more time to learn, and learning must often be consolidated at times when social interaction with peers is not required. However, such a child also finds it difficult to initiate social contacts — eye contact reinforces friendship and body positions deliver clear messages of intent. With sensitive intervention, the impact of sight loss on social development can be modified — hence the importance of time spent at Bennettswood.

This project has clarified a number of points: for example,

a. Given support and information many community pre-schools can become integration placements as the 'sameness' of children can overcome the differences presented by a major sensory disability such as blindness.
b. Every child's needs are individual, and flexibility of service is essential if the needs of the children are to be met.
c. Planning staff must have a firm understanding of the needs of all their children, including the implications of the disabilities some may have.
d. All the children's learning can be enhanced by the special provisions made for the child with special needs. In this group tactile clues and braille labels have been added to the song list. The tactile clues are used by the visually impaired children and the sighted children for whom they are an appropriate aid to reading readiness.
e. Children with special needs must have fewer peers in the group and more trained staff if they are to progress in formal learning readiness. In this group there are 12 sighted children and 3 visually impaired children. There is a pre-school teacher, an assistant and a pre-school teacher of the visually impaired.

In common with all the children in this group, Rachel, Simone and Jordina are using their pre-school experience to develop self esteem, social skills and a positive attitude towards learning. This commonality allows children with special needs to successfully claim their rightful place amongst the community, whilst still having their developmental needs met. This integration project has also helped to demystify visual impairment, whilst developing the community's awareness of visual impairment. In 1986 this model was conducted in 3 local pre-school centres.

Residential Group

While R.V.I.B. policy seeks to maintain the visually impaired child in his own home, the chosen management of a child may indicate residential placement. When this is so, it should be offered in such a way as to support the parents without guilt at their decision to so place the child. Usually these children are multiply impaired and require intensive and consistent input to develop potential.

Some children are wards of state and in R.V.I.B. care for 7 days each week, but most children return home for at least weekends to maintain family bonds. In addition, parents are invited in weekly, or for remote families for up to a week each term, to become actively involved in their child's program and to be able to continue child management procedures consistently.

CONCLUSION

The philosophy underlying the variety of services provided by the Early Childhood Development Department of the R.V.I.B. is based on recognition of the fact that the visually-impaired child is a unique individual and an integral part of the family unit. Programs for children are based on the assumption that children will learn through positive experiences, within a personalised program that is related to the individual child's development, rather than a fixed curriculum. Parents are respected for their culture and child-rearing methods, and as participants in decision-making, involved in their child's program. The educational program is based on observation and assessment, both ongoing processes that are the responsibility of all staff. There is an overall commitment to an inter-disciplinary approach among staff members, and an acknowledgement of the concept of a 'named Person' as the family contact. Staff are aware of the implications of visual impairment on communication, and understand the limitations and implications of each child's impairment. They aim to lead the children to respect themselves as they are, but also challenge them to extend themselves. Overall, the goal of the program is to choose the least restrictive environment for each individual child.

Details about programs currently available can be obtained from the Institute.

Chapter 14

EARLY TREATMENT FOR CHILDREN WITH CEREBRAL PALSY AT THE SPASTIC CENTRE OF N.S.W.

Elsie May

INTRODUCTION

Cerebral palsied children, like children suffering from other developmental disabilities, are children 'at risk'. If our goal is their optimal development, physically, cognitively and affectively, then early intervention and parent support and training should be instituted from the earliest possible age. Cerebral palsied children primarily need intervention to facilitate normal experience of movement in order to promote maximal sensory, motor and social interaction. Indeed, to counteract experiential deprivation associated with the motor disability and possible developmental delay, structured educational play activities also become a critical feature of the overall therapy program. The importance of child-directed play as a means of discovery and integrating a learned experience should be stressed.

Cerebral palsy is a developmental disability which may have concomitant learning difficulties. It is the result of a brain lesion which is non-progressive in character and which exists from earliest childhood. The motor deficit finds expression in abnormal patterns of movement and posture in association with an abnormal tone (Bobath, 1967). Children suffering from cerebral palsy are distinguished medically from those children whose physical handicap does not derive from abnormal brain function. It is estimated that very mild cerebral palsy, often equated with a neurological handicap, affects about five percent of the population. The incidence of moderate and severe cerebral palsy is almost two cases per one thousand births.

Although children affected by cerebral palsy are frequently all referred to as 'spastic', there are three main classifications (as well as mixed types):

1) spastic 2) athetoid 3) ataxic

which refer to the type of muscle abnormality found in the child. However, each child with a diagnosis of cerebral palsy is an individual and varies according to the degree of involvement and the number of limbs affected, so that the physical disability may range from a barely discernible degree of impairment to almost complete lack of voluntary motor control. Indeed, it is difficult to find two cerebral palsied children who are alike, for the impairment in brain development can assume many different forms, sometimes affecting the intelligence, vision, hearing, speech and sensorimotor skills of the disabled child (Bowley & Gardner, 1969)

There have been a number of surveys purporting to assess the relationship between intelligence and physical handicap among cerebral palsied children. The evidence indicates that there is little direct correlation between degree of physical handicap and impairment of intellectual functioning

(Phelps, 1940, O'Brien, 1945, Kirk, 1972). The most recent research suggests that two intellectual patterns can be discerned from the vastly heterogeneous population of cerebral palsied children (Brereton, 1972).

1. Those with a complex brain injury and an eccentric or unusual pattern of learning and behaviour whose level of intellectual function follows a platykurtic distribution and ranges from 0-70 IQ points. For this group, marked intellectual slowness is primarily of neurological origin and the services of a special school/class are usually required.
2. Those with good reasoning ability and good presentation despite a mild, moderate or severe physical handicap. Their level of intelligence overlaps the former group but it is normally distributed with a mean of about 90 IQ points. For this group, the deviation from normal achievement may be explained not only in terms of neurological handicap but also by the experiential limitations associated with it.

It is essential to understand that any intellectual and sensorimotor disabilities in a cerebral palsied child may not only be directly attributable to a cerebral lesion but also to an impoverished or bizarre environment arising from a disorder of movement and posture. An early medical diagnosis is of paramount importance so that early intervention techniques from a multidisciplinary team can be instituted to facilitate more normal environmental experience of movement and increase the quality and quantity of environmental interactions. Such a team can take account of both motor handicap and possible developmental delay, and work together on gross motor, fine motor, self-help, cognitive and language skills in an ordered developmental sequence. The inclusion of parents in this program is all-important, not only to ensure its application in the home but to lessen the apprehension, frustration and bewilderment that are the normal reactions for parents attempting to rear a motor disabled infant.

Early intervention in the form of physical therapy for infants with cerebral palsy has been the cornerstone of management of this disorder at the Spastic Centre of N.S.W. since the introduction of neurodevelopmental therapy by Karel and Berta Bobath (Bobath, 1967) and its subsequent extension by Quinton (personal communication), Bly (1960) and Mead (1982). This neurodevelopmental approach is best understood within the framework of motor development in normal infants.

Motor development in normal babies is sequential to a consistent progression and interaction of postural reactions following the inhibition of the primitive or involuntary reflexes (present from prenatal life and continuing after birth) by the higher centres in the cortex and brainstem (Mead, 1982). These primitive reflexes such as the startle (Moro), palmar grasp and asymmetric tonic neck reflex, which can be elicited in the early weeks of life, usually disappear by 3-4 months of age.

What is occurring as these primitive reflexes wane is a preparation for movement involving patterns of flexion and extension, the development of symmetry and mid-line orientation. At 4 months of age there is good head control, developing trunk control, the hands are midline and there is preparation for balanced lower limb movements. In the fifth and sixth months of normal development, lateral weight shifting and developing righting reactions bring in rotation within the body axis and we see emergence of equilibrium reactions which will be developing over the next five years.

Considerable sensory input contributes to the infant's acquisition of postural control. Bobath (1967) and Bly (1960) stress the sensory experience, the involvement of tactile, proprioceptive, kinesthetic, visual, auditory and vestibular systems in motor development and the importance of repetition in learning the sensation of a movement. Infants learn by adapting to the handling and the attention they receive, in dressing, feeding, being picked up and put down, during bathing and in play.

Because infants with cerebral palsy have abnormal tone as well as abnormal patterns of movement and posture, they do not acquire the normal balance between developing flexion and extension. They do not learn to raise their heads in a prone position or later in a supine one, when the normal baby learns to elongate his neck and give 'tuck' to his chin. Lack of neck and back extension and 'chin tuck' encourage the persistence of drooling and tongue thrust, inhibit the development of prehension as well as good respiration and feeding patterns, the production of voice and facial expression. Many start with an abnormal quality of extensor muscle activity but the anti-gravity flexion components do not develop sufficiently to counter-balance this. In some babies, low postural tone makes it difficult for them to acquire the necessary stability to move other parts of their body. To compensate, they learn to use their abnormal movements and their early reflexes to obtain stability and allow mobility.

The use of the asymmetric tonic neck reflex, after the first four months, to stabilise the head and shoulders enables the infant to move. As this abnormal pattern is used more frequently, it becomes stronger and 'blocks' the normal process of symmetry.

The key 'blocks' to development which need intervention are in the proximal areas — the head, shoulder girdle, the pelvis and hips, as these control the posture and development of movement in the upper and lower limbs. It is the early identification and analysis of these 'blocks' to the development of movement which makes intervention in the early months of life, before the compensation/ habit stages are established, the basis of the early intervention programs at the Spastic Centre.

A multidisciplinary approach to early intervention with cerebral palsied children takes cognisance primarily of motor handicap when planning a total educational program. Early physical, speech and occupational therapy enables parents, when attending to their children, to learn correct positioning techniques which not only assist in preventing abnormal movements, but promote a more positive parent/child interaction. Parents are shown the areas where the movement has 'gone wrong', or is not developing effectively. They are encouraged to feel the movement themselves and to observe it in other children. Periodic videos are taken to show progress, and to reinforce handling techniques. When parents own their own video equipment, they may request a film to show other family members the best way to feed, dress or carry their baby. Most mothers are given a 'diary' in which drawings or photographs and a brief description of any changes in treatment keep fathers informed and families up to date on the baby's progress and management.

Treatment in the early months involves the physiotherapists more consistently than other therapists. Emphasis is on the infant gaining control at the proximal areas, working for symmetry and rotation within the body axis, liberating the righting reactions and facilitating active movement.

Infants and children with motor delay and cerebral palsy range from mild to severe. Medical practitioners and parents should be aware that infants with mild delay, those with mild diplegia or a hemiplegia, though in need of therapy and medical supervision, behave developmentally very like normal infants. Consequently these infants for whom early intervention is likely to produce the best outcome, are often missed or are late referrals.

To show how seriously motor delay affects normal development, it should be noted that the infant with normal motor development directs his mother's responses by his behaviour and interaction.

This has been noted from as early as the first few weeks of life (Macfarlane, 1978). However, the infant with motor handicap and delay may be impeded by lack of physical development and/or control in responding in this way. Therefore, instead of initiating maternal response as the normal infant does, the motor-handicapped infant must await parent initiative. Mothers of first babies, in particular, may accept this lack of response as normal or be more accepting of wrong advice and hence perpetuate the delay. Infants with cerebral palsy may manipulate their parents by abnormal crying and reflex actions. These infants suffer privation of experience and stimulation and this has a serious effect on intellectual development (Rutter, 1975).

The more severely affected babies, with difficulty in sucking and swallowing due to retention of primitive oral reflexes, are extremely difficult to feed, so causing a feeling of rejection at a very primitive level in the mother. The baby who is difficult to change and dress, impossible to hold and cuddle, being too stiff or too floppy, may arouse fear and unhappiness. Those babies whose voluntary eye movements are affected, whether by ocular muscle inco-ordination or abnormal head posture, have difficulty in initiating eye contact with their mother. This is considered to be one of the inbuilt releasers for the maternal caring response (Macfarlane, 1978). These problems can be alleviated by early intervention and the giving of practical help to parents to assist them in dealing with day to day living and caring problems, thus reducing anxiety and emotional distress. Recognition of delayed motor development especially in at-risk infants, should occur rapidly in Australia, where most babies are under the care of a paediatrician, their family doctor or the Baby Health Centre.

The emphasis so far, has been on programs designed to minimise the difficulties arising from a motor handicap present from birth, and prevent associated experiential deprivation. Should developmental delay also be apparent in the young cerebral palsied infant, then the special educator will assist the therapist to incorporate appropriate structural play activities into the overall therapy.

Before early intervention programs are instituted, it is essential that a specialist doctor is consulted to ensure that other treatable handicaps are not present and to discuss with the parents what is wrong with their baby and how this can be alleviated. With motor handicap or delay, the specialist doctor would be the paediatric neurologist at the Children's Hospital or a doctor working in a Child Development Unit, an Area Child Health Centre, or in a specialist organisation such as the Spastic Centre of N.S.W.

Where are the Spastic Centre Services in N.S.W.

The early treatment programs within the Spastic Centre are staffed by a team which includes a doctor, physiotherapists, occupational and speech therapists, educational and clinical psychologists, an orthoptist, a social worker and, for country parents, a mothercraft nurse. In the Early Treatment clinics the team includes a teacher, thanks to recent Commonwealth funding.

These treatment programs function on 5 days a week at the Mosman* unit for metropolitan referrals, at the W.C. Allen unit, Allambie Heights, which includes metropolitan and country referrals, and at the Stuart Centre in Newcastle for referrals from Newcastle and the Hunter Region.

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* The Mosman unit will re-locate to Ryde in 1988

The Early Treatment Clinics function on 1 day a week as an outreach program at 9 Baby Health Clinics or Community Centres — Gosford, Miranda, Seven Hills, Miller, Riverstone, Regents Park, Doonside, Belmore and Granville. Most of these are outer suburbs of Sydney.

To whom do they apply?

Any infant or child with motor delay may be referred by the doctor professionally responsible and referrals come to the Medical Director of the Spastic Centre. This is to ensure that full information of the family history and details of birth history and any illness the child may have suffered may be obtained.

Who is involved in management?

Following a referral to the Medical Director and before seeing one of the medical staff, the parents will be seen or contacted by a social worker at Mosman, a social worker or clerical staff at Newcastle and the W.C. Allen Unit and a community liaison officer attached to the Early Treatment Clinics.

Following the medical consultation, the doctor, together with the parents and the therapists at the unit involved, will decide the management and treatment program needed by the particular baby. Where necessary, a home visit is made by one or more of the therapists involved with the infant. All infants with a recognised disability, or where doubt exists about development, must have their hearing, vision and developmental skills tested. Where spasticity is present or doubt exists a hip X-ray should be done. Acceptable assessment in all these areas may require recurrent testing before a final decision is reached.

Within the Spastic Centre services the team approach is fostered and encouraged. The team has regular discussion of aims and objectives as the child's treatment progresses. All therapists have overall aims of encouraging movement that is graded and controlled, and in developing appropriate social interaction. More frequent discussion will involve those in constant direct contact with the child and family such as the immediate therapy team, the special educator and, when appropriate, other members of the team.

The Physiotherapist is concerned with the analysis of movement and the planning and provision of treatment to assist the baby to gain postural control and movement. Home therapy and training of parents is a necessary adjunct to helping the parents feel comfortable in handling their baby. The physiotherapist aims to encourage the affected infant to gain active movement and variety of movement in order to provide the right sensory input and experience. Physiotherapy will be necessary in severe cases throughout the affected child's life and in mild cases until a walking pattern is established.

The Occupational Therapist is involved with upper limb function and control of fine motor movement, the development of play and the use of suitable toys, visual fixing, scanning and following, in consultation with the orthoptist, facilitating cognitive development and the learning of self-help skills. The child's seating, posture and feeding requires input from the physiotherapist, occupational therapist and speech pathologist.

The occupational therapist, in consultation with the psychologist, will establish a program of experience in areas of perception in which the child has been deprived and provide practice in areas such as motor planning and stereognosis. There will also be training in the development of self-help skills for toiletting, washing and dressing and assistance for parents with home adaptations and seating for transport.

The Speech Pathologist is involved in developing communication between the child and his/her family. Where feeding problems exist, due to abnormal postural tone, abnormal and unco-ordinated patterns of oral function and respiration, the speech pathologist will assist the mother to feed her child safely and efficiently. Development of normal oro-facial patterns during feeding is an important component of speech development. At the same time attention is given to maternal-infant interaction and the development of vocalisation during feeding and handling. Problems with hearing, language and speech development are diagnosed, and treatment programs to develop appropriate communication skills offered. Alternative or supplementary means of communication are provided where appropriate.

In the first six months of life all three therapists may be involved. The physiotherapist gives practical help for the mother in handling and posturing her baby as well as in feeding, aiding interaction and care. She will help the mother to handle her baby by showing her how to inhibit abnormal patterns of movement and to be comfortable with her child. The speech pathologist will advise on the feeding difficulties and help the mother to assist the baby to overcome and inhibit the abnormal reflexes associated with chewing and swallowing, and work closely with the mother and the physiotherapist. The occupational therapist will be involved in helping the mother to play with her infant and helping the infant to develop visuomotor skills, reaching and grasping.

Early management involving inhibition often means a complete reversal of the mother's learned management of her baby which have been shaped by his/her abnormal patterns. These changes may lead to anger and frustration in the infant, expressed by persistent crying. If this should happen, the parents will need intense support, as the extended family or neighbourhood pressures will encourage parents to comfort their baby rather than to persevere with therapeutic management. Once these changes have led to better patterns and the infant is more comfortable, tensions between the parents and their baby will lessen. The warmth of the relationship between the parents (ie. between the father and the mother as well as the parents and the child) is an equally important influence on child and family development.

The team of therapists involved with each child will work together in co-ordinating management; for example, with feeding difficulties the physiotherapist and speech pathologist would be closely involved, the physiotherapist with posture and handling and the speech pathologist with development of normal feeding patterns and treating abnormal oro-facial reflexes and unco-ordination of the lips, tongue, jaw and palate, and improving swallowing and breathing patterns. The occupational therapist will work closely with the physiotherapist in developing fine motor patterns and with the speech pathologist in developing acceptable social patterns of behaviour in eating and drinking.

As the child develops and needs change, the amount of therapy time with each discipline will vary depending on the child's and the parents' needs. It must be remembered that not all parents are able to shoulder such a heavy and unremitting burden and it must not be expected that all mothers can be translated into therapists. They have to work through their emotional trauma and must be allowed time and support to do so. If necessary, intensive help is available from the clinical psychologist for the parents and the therapy team.

The special education teacher, a member of the team in the Early Treatment clinics, works to ensure the trust and co-operation of parents by establishing a rapport with them at home and in the clinic. Individual educational programs are designed for each child within the concept of the parent as teacher. Working with the established teams allows the teacher to provide appropriate goal setting and to encourage appropriate behaviour in cerebral palsied children, particularly when observation and assessment indicate some degree of developmental delay.

One of the most effective practical methods for some mothers is to have help at home provided by the statutory agencies. The home help can attend the therapy sessions and assist with home management. Many of those who undertake this employment are very good indeed at carrying out home therapy programs which will provide parents with tremendous support at critical periods.

The Orthoptist, also a team member, tests each child's visual acuity until an accurate assessment of the child's vision is obtained, consults with the team with regard to the child's vision handicap and liaises with the child's eye specialist through the Spastic Centre's doctor who is responsible for each individual child and family. All children have their hearing tested at the National Acoustic Laboratory.

Throughout the treatment period, there is a regular review of the child's total progress and development by the doctor in consultation with the parents, therapy staff, psychologist and social worker/community liaison officer responsible for family support services. There is mutual support between doctor, team members and parents' doctor which is likely to provide the most beneficial and healthy environment for the child's development. The doctor will consult and liaise with the referring doctor and other specialists involved in the child's treatment as well as the visiting specialists to the Spastic Centre — Orthopaedic Surgeons, Eye Specialists, Neurologist and Neurosurgeon.

A member of the psychology team will test each child at intervals to assess cognitive and learning problems in close liaison with the doctor and consult with and advise the parents, special educator and therapists. The clinical psychologist will provide help for families where there are behavioural and social problems and acts as a consultant adviser to the team. As the child reaches the age of school entry, 3.5 — 5 years, the psychologist plays a most important role in assessment and, with the parent's permission, will consult and discuss with the Department of Education Officers an appropriate school placement. Once the decision with regard to school placement is made and accepted by the parents, the therapists, again with the parent's permission, will advise the class teacher about the nature of the child's handicap and its effects on seating, positioning, carrying, playing, toiletting and eating. The teachers involved in the Early Treatment teams liaise closely with the teachers at the receiving schools which assists the continuing interests of the child, the classroom teacher and the parents.

Funding

The early intervention services within the Spastic Centre were developed and later funded by the Commonwealth Government from different sources — some being almost totally subsidised, others coming from a capital grant that has not increased since 1978 although the cost of the service has increased by three times the funded amount. Additional assistance in the form of a non-recurrent grant was given in 1986. There is no State Government support for these services.

Service Delivery

Mosman is the main base for the clinical staff of the Spastic Centre of New South Wales. The three main centres — Mosman, Allambie Heights and Newcastle are accessible by car but access is difficult for those parents with a disabled infant or child who are obliged to use public transport especially those who live in the more populous Western or in the Southern regions of the City. Early Treatment clinics at Gosford and suburban centres therefore have been established to provide a service for these parents. Since they are based in local community centres they are accessible not only to the local family but also to the extended family and friends.

Because a local service such as that provided by the Early Treatment clinics increases the accessibility of the staff to others beside the immediate family, it consequently lays a greater burden on the staff in these units. The numbers of staff in each unit will vary from 1-2 full time physiotherapists and 1-2 full time occupational therapists, and a shared responsibility for all 9 outlets between 2 speech pathologists and 1 orthoptist. The very nature of the service leads to close interdisciplinary working and shared problem solving. The doctor will visit at regular intervals and the psychologist at prepared times.

There are two important considerations needing attention for others developing a similar service, such as that in the Early Treatment Clinics:

> First and foremost, the lack of a full time social work service working with the teams must, of necessity, reduce the quality of any early intervention service.
>
> Second, a better developed administrative structure, for such a far flung service, must be established to lighten the burdens of the senior physiotherapist who acts also as the co-ordinator.

Although it might mean more travelling by some parents, it may be that fewer centres running 3 days a week could give a more effective service to children and parents and provide more staff support with an improved and tighter administrative structure. This will be a consideration in the outcome of future planning.

The use of Baby Health Clinics and Community Centres, although not always preferable for Spastic Centre staff, are ideal for parents and their children since they provide a more normal and comfortable environment. Working in Baby Health Clinics and Community Centres also helps to improve liaison with other community staff, both statutory and voluntary.

CONCLUSION

This paper has attempted to outline the early intervention services provided for cerebral palsied children by the Spastic Centre of N.S.W. These are acknowledged as having a high degree of excellence which is dependent on continual training that is inter-disciplinary and involves enthusiastic and highly trained staff. Accent on the team approach to the management of the individual child's disorder is complemented by intense support for the family at all crucial times by the doctors, social workers and clinical psychologist.

I would like to express my thanks to all the staff who provided assistance in the preparation of this paper.

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Chapter 15

THE EARLY INTERVENTION PROGRAM OF THE AUTISTIC ASSOCIATION OF N.S.W.

Barbara Kennett

Over the last decade, intervention programs have assisted individual development at an early age through improved and enriched environmental conditions. These have involved educational programs that utilise task analysis, precision teaching and behavioural approaches to minimise aberrant behaviours. However, successful early intervention is equally dependent on early identification and the recognition of the young child's unique cluster of behaviours.

One problem facing professionals is the difficulty of accurately diagnosing autistic features in the very young child. In general, such children exhibit three major areas of disability, namely severe communication problems, inability to relate to others appropriately and ritualistic or obsessive behaviours. Given the recently reported research on the development of neonates, including awareness of objects and people together with their ability to reciprocate socially as early as the first two weeks of life (Brazelton, 1984), the fact that children with autistic features are still not being identified until two to three years of age is a major concern.

Differential diagnosis, or worse, no diagnosis at all, is due in part to two factors. First, unless the behaviours are extreme, they are unlikely to be detected in a routine half-hour visit to the general practitioner or community nurse. The parents are often regarded as 'overly anxious' and told, 'Don't worry, he will grow out of it'. Secondly, the professionals themselves may be worried but, because of the child's young age, avoid or delay telling the parents either because they don't want to worry them unnecessarily or they feel that the parents are not ready to accept the fact that their child has a developmental delay or disability. This denigrates the parents, defeating the 'positive model' and introducing a 'defensive model' (Brazelton, 1984). Frequently, the problems and limitations of the autistic young child remain unidentified during the first three years of life and valuable time for early intervention is lost. As Bloom (1964) emphasised, the most critical period of a child's development occurs in the first four years of life.

Parents of children who have been delayed in their introduction to the relevant infant programs because of a non-specific or inaccurate diagnosis or the unwillingness of the professional to make any diagnosis at all, tend to consult with a variety of different professionals. This results in the parents becoming totally confused about the best way to intervene because the advice given frequently varies with the perspective of the professionals. Unfortunately, a frequent practice has been to fit the child and family into a program which reflects the therapist's uniform orientation, rather than designing programs to facilitate the learning of new skills and appropriate behaviours that reflect the special needs and specific environment of the autistic child and family (Kennett, 1982).

The recognition of autism at the earliest possible age is essential. The autistic individual who is identified at a later age is often, after gaining appropriate competencies, only able to utilise these skills in one environment for, when older, they lack flexibility and initiative in the application of what they know (Rutter, 1985). With early identification, the autistic young child learns to cope more adequately with environment changes involving transfer of skills from the home to the pre-school and subsequently to a variety of integration and mainstream experiences (Kennett, 1985).

This chapter focuses primarily on the specialist early intervention program provided by the Autistic Association of New South Wales. While there are programs for autistic infant children in other States, each model has developed individually to respond to its own specific State need. They are all significantly different from the one described in this chapter.

The New South Wales program was implemented in 1975 with the goals being to:

1. provide an intensive, individualised assessment and therapy for preschool children with multiple, behavioural and communication problems;
2. include parents in the assessment and therapy process as much as possible, since the service recognises that parents have the ultimate responsibility for the child and the greatest contact with their child;
3. facilitate access to appropriate community welfare services; promote, through support and counselling, the stable mental health of family members and the good functioning of the family as a unit;
4. **achieve optimal development in the child and to facilitate his/her eventual entry into the most advantageous and least restrictive learning environment.**

Implementation of services is achieved by a staff team of five; since mid-1975, 216 children have been involved in the program and staff numbers have increased from one peripatetic to three, with one teaching assistant and welfare worker. All staff are expected to attend in-service training courses offered both by the Association and other bodies.

At inception of the service in 1975, the Association was the only organisation which offered a home-based service to families with a behaviourally disturbed, developmentally delayed child. At the time, caretakers stated that the benefits gained by taking a difficult child to a weekly therapy session at a centre some distance from their home certainly were not sufficient to offset the trauma of coping with one or two children on public transport or dealing with extreme tantrums in public.

Children are referred to the program because of their extreme behaviour problems, social deficits and disordered and/or delayed communication. These criteria for enrolment would, by definition, include a percentage of children with early infantile autism. However, the overlap among behaviour disorders, communication problems and developmental delay in young children is well documented.

> While simplistic explanations of cause and effect that imply that problems in one area can account completely for those in another (eg. that a child's resistive behaviour causes his or her receptive language delay, that a child's distractibility causes his overall developmental delay) may be adequate for a small number of children, it is becoming more and more widely recognised that this is not the case for many others.
>
> (Lord, 1983, p.57)

Therefore, the majority of the children on the program can only be described as 'odd' or 'different', not fitting into any clear-cut diagnostic category (Wing, 1980a). These children respond well to specialised home-based intervention, usually progressing on to a less restrictive environment, firstly into preschool and eventually to school at the appropriate age.

Client Population

The users of the Association's early intervention program are the child and his/her family from the age of diagnosis until four or five years of age. Some of the specific groups which the service has developed expertise to assist include:

a. children with a combination of significant behaviour problems, severe language delay and uneven patterns of abilities;

b. those with a severe social deficit, obsessive and disordered language and cognitive abilities which generally fall within normal range, eg. Asperger's Syndrome;

c. children with moderate to severe retardation, with secondary autistic features; this group also includes girls with diagnosed Rett Sydnrome: this syndrome is described as 'cerebral atrophy' characterised by autistic behaviour, apraxia of gait, loss of facial expression and stereotyped use of hands (Hagberg, Aicardi, Dias & Ramos, 1983);

d. those children who can only be classed as 'different'; they can initiate social contact with selected adults, but the quality of that interaction is odd; they do communicate, but only on their terms; their play can be imaginative, but at the same time, extremely rigid and exclusive to themselves;

e. families whose use of transport, either public or private, is limited by the child's behavioural disturbance and thus are excluded from attending centre-based programs;

f. children and families for whom specific therapy services are unavailable because of distance; these include those in outlying suburbs and country areas of the state: close liaison with generic services and their professionals, often a community nurse, enables an individualised structured program to be offered and monitored on a monthly or quarterly basis;

g. families whose perception of their child has been unrealistic at time of referral and later is affected by the increasing problems presented; for example, the return to the service of a child who had been withdrawn from an early intervention program including our own, because of disillusion with the slow progress inherent in a very handicapped child.

The Association is conducting a ten year longitudinal study on its early intervention service. At this time, 105 enrolled children on the program from the Greater Sydney Metropolitan area have been included. Country children have been excluded, as mentioned earlier, because, of necessity, the service operates in a different manner. Preliminary results of the study over a four year period are presented in the following discussion.

Sex Ratio

There were 91 boys in the study and 14 girls. While this is a higher male/female ratio than usually reported for autistic individuals (Lotter, 1966), it must be noted that this service provides for children who are not necessarily diagnosed as autistic.

Referrals

The majority of all referrals come from Metropolitan Diagnostic and Assessment Centres for Developmental Disabilities and the Child Development Unit (C.D.U.) of the Royal Alexandra Hospital for Children (R.A.H.C.), which has no such locally defined region. Many of the children referred on to the service from C.D.U. present initially to their local paediatrician as speech delay/behaviour problems, with better functioning skills. Thus they would not be referred to Regional Assessment Centres as they would not be regarded as 'globally delayed'.

TABLE 1 Distribution of children enrolled in program by source of referral

Source of Referral	f	%
R.A.H.C. C.D.U.	46	43.8
Regional Assessment Centres	44	41.9
Medical Specialists	7	6.9
Department of Education	2	1.9
Y.A.C.S.	2	1.9
Parents	4	3.8

Age of Referral

In an accountability study (Whitmont, 1981) using information over a six year period, the average age at entry was 55 months. The present study found that the average age at referral was 36 months, with a minimum age of 7 months and a maximum of 57 months. However, identification now occurs earlier and referral age has been reduced by 19 months.

Time on Program

The length of time children spend on the program has ranged from a minimum of 3 months to a maximum of 32 months; the average length of stay was 13.5 months. This shows an increase of 5.5 months over the previous study. From time to time, children are referred to the service with a specific set of behaviour problems which usually require a short, intense, behaviour management program, lasting anything up to two months. These are referred to as crisis cases and are not included in the data reported above.

Exits

Of the 105 children in this present study, 83 have exited from the program. The remaining 22 are still enrolled on the service. Data on places of exit are shown in Table 2.

TABLE 2 Distribution of children learning program by subsequent placement

Exits to	f	%
Association School	35	42.2
School for Specific Purposes	24	28.9
Special Class/Normal School	4	4.8
Normal School/Preschool	16	19.3
Other Programs	3	3.6
Unknown	1	1.2

The percentage of children going on to an Autistic Association school has remained relatively constant since 1981. In the previous accountability study, it was noted: '36% of children leaving home management are immediately enrolled in one of our schools, while 41% ultimately do so.' While it is obvious that there is a great variation in outcome and eventual placement, some autistic children remain very handicapped and require special schooling specifically for their needs.

Procedures

Upon referral, all children who have not already had a full diagnostic assessment are immediately referred to their appropriate assessment centre.

At entry, a developmental assessment The Adaptive Behaviour Scale for Infants (ABSI), (Leland, Shoaee, McElwain & Christie, 1980) is administered to parents/caregivers. This provides the parents with an opportunity to involve them in the assessment of their child and in subsequent therapy, and also for professionals to explore the knowledge and beliefs parents have about their child. Involving them at this stage also helps to demystify the process of assessment itself. All cognitive assessments are also administered with either the parents present in the room or, if the child is easily distracted, observing through a one-way mirror.

The ABSI is a criterion-based test designed to record appropriate age behavioural patterns by listing current functioning and on-going behaviour of an infant. Such recordings provide broad indications of the antecedents to behaviours and give an indication of possible succeeding behaviours important for the effective design of individual training programs. The Scale is developmentally ordered, and is divided into two main parts: Part I which records appropriate and desired behaviours under the sub-domains of Independent Functioning, Physical Development, Communication Skills, Conceptual Skills, Play, Self Direction and Personal Responsibility and Socialisation; and Part II which allows for recording of inappropriate and undesired behaviours.

The ABSI was chosen as the main assessment tool because it could be administered by any professional, encouraged maximum parent input and, when administered at regular 6-9 monthly intervals, measured even minimal progress. It forms the basis for individualised programs and also proves a successful screening tool for children with a mild intellectual handicap and autistic features. In an exploratory study of 40 mildly handicapped children using the ABSI as a diagnostic tool, the results provided support for the claim that the ABSI yields a special profile which distinguishes autistic from non-autistic young children with similar levels of handicaps. The Autistic children demonstrated a set of behaviours that were distinct from those of other mildly handicapped young children, as evident in high scores on Physical Development and Self Direction and low scores on Communication and Conceptual Skills, Play and Personal Responsibility and Socialisation (Kennett, 1984). The importance of having various types of assessment is recognised. However, more accurate diagnosis means that curricular and program plans can be more effectively evaluated and more selective teaching strategies designed.

Diagnostic data collected at entry include:

Referral records — name of family, referral source and date and presenting problems.

Child history — medical information, past assessments, other professionals currently involved and present pre-school, if currently attending.

Family records — nationality, language spoken, educational level of parents, names and ages of family members and birth order, and any presenting problems with siblings.

This information is recorded by the welfare worker on the team at an initial visit. At this time, the welfare worker is also prepared to answer all the parents' concerns which have emerged since they were told their child would benefit from special help a couple of weeks earlier. The specialised program and method of delivery — ie. number of visits per week, home visits, preschool visits — are also negotiated with the family. The welfare worker acquaints the parents with any expectations regarding continuation of programs implemented by the teacher and a follow up visit is made after three months to ensure that the program is best meeting the needs of the child and its family.

The role of the welfare worker also includes assisting the family in arranging temporary care, seeking suitable pre-schools and schools for integration and alerting parents to the appropriate government benefits. This necessitates having a comprehensive knowledge of community welfare services, thereby facilitating the family's easy access to generic services. In addition, the welfare worker provides the parents with an opportunity to express any anxiety they may have with their child's program which they may be reluctant to express to teaching staff.

After this initial visit, an individual program is designed in consultation with the psychologist, parents and teacher/counsellor. While the program is directed to remediation of specific developmental delay, the child's global development is also addressed. The program is implemented by the teacher/counsellor, who works with the child and family in their home for a minimum of one half-day per week. The progress of each child is monitored and recorded weekly, and then discussed at a monthly case conference, which is attended by all staff on the program including the Association's psychologist. Other professionals, such as speech therapist and occupational therapist who may be working with the child, are also encouraged to attend. All records of an individual child's progress are continuous and available to the parents at any time. Where there is a requirement of reinforcement on an intense basis for a specific program and/or extension of the program into the community, pre-school or school, an experienced child-care assistant provides additional visits. These are under the supervision of the psychologist and/or the child's teacher/counsellor. Every nine months the ABSI is re-administered and the child is re-assessed by the original referring agency. However, an earlier review is arranged when requested by parents, in times of crisis, or when the child's progress has been exceptionally rapid.

Parent Involvement

One of the major aims of the service is to involve parents as co-therapists. After all, they have to manage their child on the remaining days of the week and thus need the requisite skills to do so. However, it must be recognised that these parents have been trying to cope with a very difficult child over the past two or three years. This is often a child who has been difficult to feed and toilet train, would not sleep through the night (especially in his or her own bed), staged amazing tantrums in public, was unresponsive and unrewarding to be with and needed to be watched eighteen hours a day. 'The lack of responsiveness and reciprocity of young children with autistic characteristics is a particular cause of confusion, anguish and despair to many parents' (Allen et al., 1985, p.3). Therefore, if the parents do not want to involve themselves actively with the implementation of the programs at first, they are not pressured to do so. Given breathing space, time and, meanwhile, observing that their child can learn to attend to simple directions, indicate a need to go to the toilet or tolerate a routine being disrupted, they all eventually indicate a willingness to participate. If parents are to become independent of professionals, then the skills they gain at this time in dealing with their immediate problems will hopefully assist them in managing the next set of problems when the child has moved on to school.

Professionals working in the child's home must be extremely sensitive to the needs of the family members so that the handicapped child does not become the focus of attention, but rather an accepted member of the family. Care must also be taken by the teacher/counsellor to ensure that they are not regarded as having all the answers: 'Of course, he will use the toilet for you, but he won't for me!' (Brazelton, 1984).

Language Programs

The autistic child's response to language programs is extremely variable. Approximately 50% of these children never gain useful language, while of those that do, few choose to use it to communicate socially (Wing, 1980b). Therefore, language programs for children who do possess some early or pre-language skills such as imitation, echoed words and some play skills, need to address two specific areas. First, the child needs to gain some words but, more importantly, he must want to use those words for communication. Many autistic children have a large vocabulary (200-300 words) but their spontaneous utterances may be limited to one- or two-word phrases for a required need. The immediate aim is not to increase the number of words, but rather to increase the number of utterances per day.

The TELL program (Cairns & Pieterse, 1984) has been found to be very useful for children who are beginning to use language. For autistic children's language, which is disordered as well as delayed, the program encourages normal language development.

For the severely handicapped autistic child who will probably never verbalise, a functional language program is initiated. First, the particular environment in which the child functions must be considered. Secondly, the child's needs which must be expressed in that limited environment have to be assessed (Allen, 1985). The skills the child already has must be assessed before the appropriate communication system or combination of systems can be selected. For example, are the child's fine motor skills adequate for signing? Does he have good visual perception and can he scan? These must be considered before introducing a visual system. Use of one system does not necessarily replace all others and non-oral communication systems should always be paired with speech.

Communication can be defined as an interaction in which signals are goal-directed from one person to another. It is a two-way process, so not only does the child need a system of communicating with us, but must also be able to understand our communications. Programs encouraging the child to communicate with others include use of:

a. gestures: nodding 'yes' to accept goods or services or shaking head for 'no'.
b. visual: indicating by pointing or tapping a choice of photo representing items or activities preferred.
c. use of memory writer.

(Carroll, Roberts & Evans, 1984)

Behaviour Programs

Behaviour programs in autistic children are as varied and unique as the individual child and the behavioural program designed to be effective in changing the behaviour is only bound by the teacher's imagination and ingenuity. However, undesirable behaviours fall into three main categories:

1. The **inability to generalise skills**; this is common to all autistic children. Their learning in most cases is situation-specific. Handleman and Harris (1980) demonstrated that generalisation can occur if children are taught in a functional way

across settings, using consistent cues and rewards.

2. The **rigid and obsessional manner in which some of these children organise their lives.** Different methods can be used, such as graded change or introduction of alternative behaviours which interfere with the obsession. However, the long term goal is to **minimise** the behaviour, rather than **eliminate**. Although different methods can be used, all must be introduced step by tiny step (Rutter, 1985). Successful intervention also involves the use of complex record keeping and charting over and above that which would be required when teaching a new skill. Frequently, when an alternative behaviour is taught to replace the obsessive behaviour, it becomes obsessive itself. Therefore, great care must be taken to avoid this obsessional displacement.
3. **Behaviours that are socially maladaptive.** These must be addressed. It is essential for the teacher or therapist working with the child to have a thorough knowledge of what elements in the environment precipitate the onset of the behaviour. A functional analysis must always be undertaken before a behavioural program is designed to teach autistic children coping skills to deal with a situation.

The program designed to control disruptive behaviours should first ensure that it provides accurate and consistent feedback to the child regarding what is and what is not acceptable. It must also include the teaching of alternative responses to those that are unacceptable. Then, finally, the program must identify some positive responses the child already has in his repertoire, so these can be immediately rewarded. Use of material rewards, such as sweets, is not always necessary nor desirable. Autistic children often respond to social praise and social reinforcements, such as back-scratching or tickles. Reinforcement should become intermittent and steps should be taken to make acceptable behaviour rewarding in its own right (Rutter, 1985). For educational programs to be effective with autistic children, they require individual teaching, a deliberate intrusion into the child's world, steps of each task need to be smaller and more precise than those generally used with moderately intellectually handicapped children and, most importantly, they must be error-free.

Evaluation of Program

When evaluating an early intervention program, the child's progress in overall development and social adjustment is of utmost importance; however, parental satisfaction cannot be ignored. The Home Management Program of the Autistic Association has been examined by a research worker appointed by the Commonwealth Schools Commission's Severely Handicapped Fund Committee in New South Wales during an evaluation of funded programs. In her review of the program for the Committee, Ferguson (1985) reported:

> The response rate from parents of children on this program was exceedingly good: 11 questionnaires were sent and 10 returned, a response rate of just over 90%, compared with an overall response rate of just over 50%. The average age of the children covered by these responses was 3.5 years and eight of the children had been on the program for at least 12 months. The majority of the children (60%) had one sibling still living at home: two had two siblings still living at home, while the remaining two were only children. Three of the children were receiving some additional therapy services and six of the children were attending a regular preschool while on the Home Program. Two of these also attended playgroup. Half of the children had commenced full-time school at the time the questionnaire was returned and thus were no longer on the Home Management Program.

Overall, the parents reported that they were very satisfied with all aspects of their child's educational program: the only aspect with which they appeared to be less than completely satisfied being the number of hours available per week.

> The main advantages to the children of participating in the program were reported to be a greater degree of awareness of, and interaction with, others (particularly siblings and other family members), better ability to communicate, better behaviour (fewer tantrums and aggressive behaviours) and a greater degree of independence.
>
> Many advantages to the families were also reported. For example, most parents reported that their child was now easier to manage. Other advantages mentioned were less stress, more positive family interaction and the chance for parents to acquire skills, thus enabling them to assist their child themselves. Only one family reported any disadvantage to the child (that he tended to get tired) and only one disadvantage to the family (that the program required more of their time).
>
> One positive feature of this program that was mentioned by a number of parents was the fact that the service is provided in the child's home. This means a maximum degree of involvement by the parents and the reassurance of familiar surroundings to the child. In addition, there appears to be a high degree of communication between the teachers from the Home Program and the other professionals involved with the children: regular contact is reported on a weekly or monthly basis.
>
> One parent commented particularly on this aspect of the program, reporting that the three services with which her child is involved 'all complement each other. The contact between them is good and (they) listen to one another'. Such communication between professionals servicing the same child is essential if the child is to receive a coherent, co-ordinated program.
>
> All parents reported improvements in their child's behaviour/skill levels, with most children being considered to be 'better' or 'much better' in all areas except 'ability to move'. As the majority of these children do not appear to have had any serious problems with mobility, this was not likely to have been an area of program focus for this particular group. The answers to this question on the effects of the program on the child are summarised below: (n=10).
>
> | | **Much Better** | **Better** | **The Same** |
> |---|---|---|---|
> | Co-operativeness | 7 | 3 | — |
> | Ability to Move | 3 | 2 | 5 |
> | Do Things for Self | 5 | 3 | 2 |
> | Communication of Needs | 5 | 5 | — |
> | Awareness of Others | 7 | 2 | 1 |
> | Occupies Self | 6 | 1 | 3 |
> | Interest in Surroundings | 8 | 1 | 1 |
> | Participation in Activities | 5 | 4 | 1 |
>
> In summary, the parent responses to this questionnaire appear to provide very positive evidence of the success of this Home Management Program provided by the Autistic Association.

This success of this project is reflected in the comments of a parent:

> The changes in D. never came overnight and not easily but he has changed from a kid that I swear I could have killed sometimes to a child whom I love and (I) rejoice in the littlest things that he does now.

CONCLUSION

In recent studies comparing the long term benefits of home-based programs with traditional centre-based programs servicing young autistic children, Howlin (1980) and Rutter (1980; 1981) found that the home-based programs were superior on several measures. Behavioural programs showed the most improvement, whilst though there was little difference between groups on language acquisition, the home-based group were found to use language in a more social context. Obviously, opportunities for learning in a natural setting through such activities as shopping, helping mummy, bedtime and feeding programs are greatly enhanced. While the severely handicapped autistic child will probably never gain useful language, the appropriate home program can substantially reduce behavioural problems and therefore improve social functioning (Rutter, 1985).

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Chapter 16

THE HANDICAPPED CHILD AND EARLY LANGUAGE INTERVENTION PROGRAMS

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The widespread provision of early intervention programs for young developmentally delayed children in the 1970s provided an impetus for research into the development of early language and communication skills. Poor communication skills were viewed as an inherent characteristic of this population, and Chomsky's (1957) proposition that language knowledge was innate, developing through a process of maturation, had not encouraged the development of intervention procedures. Early attempts at language programming were limited to the provision of a stimulating or language enriched environment. Mittler (1975) has strongly criticised this 'language bath' approach, on the basis of evidence that the developmentally delayed are unable to benefit from incidental learning, whereas they are capable of learning when the environment is carefully structured. This point was substantiated in the evaluation studies of Headstart programs which demonstrated that those programs which incorporated a structured language teaching component were more effective than those which did not (ABT Associates, 1977).

Highly structured language training programs such a those of Bricker and Bricker (1970), Guess, Sailor and Baer (1976), Gray and Ryan (1973), Kent (1974) and Stremel and Waryas (1974) emerged as a result of experimental research which has verified Skinner's proposition that language was an operant behaviour and could be taught by the environmental manipulation of stimulus and response, and the use of such techniques as imitation, shaping, prompting, fading and reinforcement (Skinner, 1957). Reviewing these research studies, Garcia and de Haven (1974) and Snyder, Lovitt and Smith (1975) reported moderate success in the establishment of receptive and expressive language skills but found that these newly acquired skills did not tend to generalise to spontaneous conversational behaviour. This failure, combined with the contribution being made to the language acquisition debate by psycholinguists such as Bowerman (1973), Brown (1973), Bruner (1975), Nelson (1973) and Schlesinger (1974) led to a change in emphasis in language programming, away from the more traditional syntactic approach that had been of central importance in behavioural theory towards an acknowledgement of the fundamental importance of the semantic and pragmatic aspects. The importance of cognitive factors was emphasised and early speech was seen to develop as a result of the child's active involvement with people and objects in his or her environment. A further emphasis on social factors, with an understanding of the crucial role played by the significant adult in the child's early language learning environment, led to the development by McLean and Snyder McLean (1978) of the transactional model for early language acquisition.

The transactional model, which best exemplifies current thinking about early language intervention for developmentally delayed children, was derived from a psycholinguistic base and emphasised the conceptual, social and linguistic aspects of language development. Programs derived from the model provided experiences to ensure that all three aspects of language were included in the training procedures. Examples of recent programs based on the transactional approach include those by Baker, Brightman, Carroll, Heifetz and Hinshaw (1978), Cooper, Moodley and Reynell (1978), Horstmeier and MacDonald (1975) and Jeffree and McConkey (1976). In their 1978 review of current programs, McLean and Snyder McLean stated that Horstmeier and MacDonald's Environmental Language Intervention Program, (ELIP) (1978) came closest to fulfilling the program criteria required by the transactional model for effective language intervention. This program was used in the early developmental stages of language intervention, initiated at the Special Education Centre at Macquarie University, Sydney. As experience was gained over a period of five years, working in a variety of settings with children of varying ability of levels and backgrounds, some modifications to the intervention procedures were made. These were concerned with a more detailed breakdown of skills at the pre-verbal level and an increasing reluctance to view receptive and expressive skills as separate entities requiring discrete and separate sequential training. At a more advanced level, there was an acknowledgement of the importance of communicative intentions, the pragmatic use of language, and some programming of early morphological rules. The use of signing with children who experience excessive difficulty in developing expressive language was adopted. This modified program is described in a program entitled 'Learning to Talk', (Bochner, Price & Salamon, 1988) and is accompanied by a series of videotapes which illustrate the assessment and intervention procedures from pre-requisite skills to the use of extended sentences and early morphological rules.

LANGUAGE INTERVENTION AT THE SPECIAL EDUCATION CENTRE, MACQUARIE UNIVERSITY, SYDNEY, 1979-1985

The initial intervention project was established in response to a request for assistance in the establishment of early language skills for a group of young moderately developmentally-delayed children who were outpatients at a large residential hospital for the mentally retarded in Sydney. Anxiety about their children's delay in learning to talk had been conveyed by parents to the paediatrician in charge, who perceived a gap in the range of services available to this population. The project was conducted initially in a pre-school room within the institution, was replicated in the latter half of the year at the Special Education Centre and was funded by the Apex Foundation for Research into Mental Retardation (Price & Bochner, 1984). In 1980 the program was re-located at a community-based diagnostic and assessment centre for the mentally retarded and continues to operate through the Laurel House Early Language Group funded by the NSW Department of Youth and Community Services (Bochner, Price & Salamon, 1987). A similar service was also established at the Special Education Centre, Macquarie University.

The program in operation at the community health centre was run on an individual appointment basis for parent and child, while, at the Special Education Centre, several variations on this theme have been practised. The preschool classroom has had a program for 4-5-year-old preschoolers who were at risk for failure on entry into school and these children attend a full 3-day classroom program, with particular emphasis on delayed language skills, but with less contact with parents than occurs in the parent-based intervention program, although frequent meetings with parents were held, and language target information was shared, to ensure environmental application. The mother-toddler program, for which there was such a strong demand in the community, was also conducted each year in the preschool classroom at the Special Education Centre with individual programming for each mother and child, as well as group sessions for the parents (Bochner, Price, Salamon & Richardson, 1986).

In 1984, a new model was adopted in the Special Education Centre. This was in response to the experience gained in previous years which indicated that the children who had been in our programs were still experiencing difficulty in adjusting to preschool programs, and lacked the social group skills. A two-day model was established in which children came with their parents and attended a group pre-school session, while their parents observed what was taking place in the classroom, had group discussions and individual language intervention sessions, with targets being set for both the home and classroom settings (Bochner, 1987).

Target population

Over a 6-year period more than 150 children were seen in the various programs, excluding those attending the 3-day program in the Special Education Centre. The children varied in age from 16 months to 5 years. The developmental levels ranged from severely and profoundly retarded to children with normal intelligence but experiencing a specific problem acquiring early language skills.

The children presented with a variety of known handicapping conditions which are frequently associated with delays in language acquisition, including Down Syndrome, spina bifida, cerebral palsy, as well as a number of children for whom there was no known cause of their language difficulties. At a purely practical level, a member of the family, preferably someone who was the child's primary caregiver, had to be able to attend the weekly meetings. Since discussions were conducted in English, this person also had to be relatively fluent in English, though program objectives could be implemented in the language used at home by family members. Families came from all socio-economic levels, some with English as a second language and a minority of single-parent families.

Staff

The programs have been staffed by academic staff attached to the Special Education Centre, professionally-trained preschool staff and assistants, together with student volunteers.

PROGRAM PROCEDURE

1. Assessment

Children were assessed on entry to the program, at the end of the intervention period (approximately 5-6 months after the initial assessment) and where possible, 12 months after intervention ended (to provide a measure of the children's language development following intervention). Both informal and formal assessment procedures were used. In general, the informal procedures yielded information that provided a basis for programming, while the formal procedures were used to document the child's performance levels, as part of the research aspect of the project. Informal assessments included a parent questionnaire, ten-minute language sample and unstructured or semi-structured observation of relevant skills (e.g play or interaction with adults). Formal assessments included the Sequenced Inventory of Communication Development (SICD; Hedrick, Prather & Tobin, 1975), the Revised Gesell and Amatruda Developmental and Neurological Examination (Gesell Scales; Knoblock, Stevens & Malone, 1980), Environmental Pre-language Battery (EPB); (Horstmeier & MacDonald, 1974) and/or Environmental Language Inventory (ELI; MacDonald, 1974). The first two of these tests were norm-referenced and provided a basis for comparison of children in the intervention project with other groups of children who had developed language skills at a normal rate, while the latter two were criterion-based tests and provided information about the child's acquisition of a number of pre-language and early language skills.

2. Mode of Operation

The program comprised individual hourly appointments on a weekly basis for a period of 12 weeks. The first two weeks were used to assess the child, and the following 10 appointments were parent training sessions. After the intensive 12-week period, visits were arranged at fortnightly and then monthly intervals according to the need expressed by each parent. The group programs met for about 2 hours to allow group and individual discussion time for the parents and group play and 'morning tea' time for the children. Most of the topics covered in group discussions were covered with parents attending on an individual basis. Discussion also covered problem areas raised by parents such as behaviour problems, toilet training, bed-time routines, stress associated with single parenting or marital breakdown.

3. Program content

The project followed the sequence outlined in Bochner, Price and Salamon (1988). This program was organised around five sequentially-ordered levels that moved from the prerequisite skills of looking together with an adult at an interesting object or event, to the more complex skills of asking and answering questions. Intervention activities were embedded in games that could be played with just one child or with a group of children, or were built into recurring daily events. Examples of games used in the program include toys that could be activated by adult or child (a jack-in-the-box) or operated in a turn-taking routine (rolling a ball, pushing a car over a bridge), dolls or stuffed toys with equipment for domestic play (box for a bed, cup and spoon, brush, flannel), simple board games (lottos, snap cards) finger plays and nursery rhymes and a variety of pictures and books that could be used in games or for looking at and storytelling.

During the mothers' group and individual sessions, a series of topics were covered which had been selected in terms of the goals of the language program, but also in recognition of some of the specific issues that were identified as a result of working with the mothers, from the questions that were asked, particular difficulties presented by some children, or topics of general interest. While modifications were made for some groups, according to the specific needs and interests of members, a general outline of the topics covered is set out below, together with a brief description of the activity associated with each topic that was given to be carried out at home during the following week. The specific play task given to each mother was tailored in terms of the current objectives for her child, and simple, clear instructions were recorded in a 'home book'. Where appropriate, suitable toys or other materials were lent to be taken home, and staff demonstrated use of these toys with the child, or helped the mother to introduce the new game to the child during the latter part of the morning session. Every effort was made to ensure that the play tasks set each week were appropriate in terms of the child's current skills and had a high interest level, since it was important that both mother and child enjoyed the activity and that it did not provide a source of tension or frustration for either. Topics covered at the weekly group meetings, and an associated activity to be carried out at home included:

Normal language development
Selecting language objectives
Talking to children
Play Reading a book
Listening skills
Behaviour management (details are set out in Bochner, Price, Salamon & Richardson 1986)

The primary thrust of the program was to enhance their understanding of the stages of early language, how these skills were acquired and how they can facilitate their child's learning by involving the child in appropriate activities. The importance of carrying this learning into the child's everyday life was strongly emphasised. Strategies and activities were demonstrated to parents by staff working with the individual children. Where a parent had a particular problem interacting with his or her child, this aspect was more heavily emphasised. An important aspect of the project was the careful planning that went into each session. At the end of each session all the staff met to review the day's events, discuss the program being developed for individual children, plan the tasks to be introduced at the next session, and discuss general issues in the operation of the project.

RESULTS

Detailed results of particular groups of children who participated in the programs described above have been reported elsewhere (Bochner, Price, Salamon & Brownell, 1981; Bochner et al, 1986, 1987; Price & Bochner 1984). Further detailed reports are currently in preparation but the overall findings have indicated that the mean developmental rate for receptive and expressive skills, as measured by the S.I.C.D., has been equal to or better than the rate that would be expected of normally developing children. The developmental rate for communication skills during the intervention period was obtained from receptive and expressive skills by calculating the difference between the developmental rate obtained at pre- and post-test (RCA/ECA over chronological age) divided by the length of time that the child was in intervention. The expected normal rate of development would be 1.O month per calendar month with language skills increasing at the same rate as chronological age. For all groups of children, except those in the severe range of retardation, progress during the intervention period has ranged from 0.9 to 2.7 months per calendar month, with greater increases in expressive than receptive skills. This was to be expected since the focus of the program was on expressive language skills, which usually lagged behind receptive skills at pre and post-test. This rate of progress was, in general, not maintained, however, over the 12 month period following intervention, except for those children who had reached the 2-3 word utterance stage by the end of the intervention period. An increase in intelligibility and mean length of utterance was evident for 90% of the children.

DISCUSSION

The results achieved for a large group of children attending early language intervention programs over a number of years, suggest that the parent-based intervention procedures adopted have been effective in increasing the rate at which their language-delayed children acquired new communication skills. The fact that the increased rate of progress is not maintained by all children when involvement in the program ceases is a matter of serious concern and suggests the need for clarification of the reasons and then modification to current intervention procedures. It is imperative that a research approach be maintained during the implementation of such intervention programs, and that findings are continuously incorporated into modified programs. As knowledge about the intricacies of early language acquisition increases, so should our efficiency in facilitating it be improved, in those children who experience difficulty acquiring these skills. Many problems still require a solution. Some of these will be discussed in the next section.

PROBLEMS AND ISSUES

1. Methodology — the problem of demonstrating effectiveness
    a) Results from the SICD over the intervention period suggest that gains approximating, and in some cases exceeding, those expected from normally developing children, provide strong evidence of program effectiveness.
    b) Individual variation within the target population makes control group studies exceedingly difficult. Delayed entry into our programs is currently taking place, due to lengthy waiting lists; and comparisons of progress during these periods may be informative.
2. Problem of reduced rate of progress in period following intervention
    a) This adds weight to the suggestion that the intervention procedures are effective.
    b) Supports the view that developmentally delayed children have difficulty acquiring language skills without some structuring of their experiences.
3. Problem of deciding how long an intensive intervention program should continue
    a) Further investigation is needed to ascertain whether there is a developmental point at which language 'takes off' and becomes self generating. Our data suggests that this may occur when children are using a variety of 2-3 word utterances and a number of semantic-grammatical rules. If this is the case, then contact with the intervention program should be maintained on a regular, but not necessarily weekly, basis until this stage is reached.
    b) Pressure on parents attending a variety of services must be carefully monitored and adequate support and counselling provided when necessary.
4. Problem of individual variation
    a) This is masked by the presentation of group results. It is crucial that attempts be made to try and identify factors which lead to fast and slow progress, and to try and modify our intervention procedures so that children currently not progressing can be helped.
    b) Research is currently proceeding at the Special Education Centre to try and identify different interaction patterns between mother-child dyads which may be instrumental in facilitating or inhibiting progress. Specific factors under investigation are the way joint attention is negotiated, the strategies mothers use when a breakdown in communication occurs, types of feedback, and change in patterns in differing contexts.

FUTURE DIRECTIONS

Research into mother-child interaction patterns may prove crucial in providing the information needed to modify our current procedures to ensure greater success.

While we strive to unravel the complicated picture of how early language is acquired, we need to continue our intervention efforts, fed by faith and constantly modifying our procedures in the light of research findings.

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Chapter 17

COMMUNICATION CAMPS: AN ALTERNATIVE FORM OF SERVICE DELIVERY

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Although the precise number of individuals in Australia who are in need of communication training is not known, data from the Health Commission of Victoria (1982) has suggested that approximately 10% of the Victorian population between the ages of 0-14 are in need of 'specialised services'. This figure of 10% is in general agreement with the incidence reported in other countries. Using data from the Health Commission of Victoria (1982), Table 1 was devised to demonstrate the categories utilised by the Health Commission. This table provides the estimated incidence figures, the extrapolated number of children (aged 0-14) in Victoria in each category and the percentage of the total population in need of 'specialised service' each category represents.

Table 1. **Health Commission of Victoria data.**

'Label'	Estimated incidence figure	Extrapolated no. of children aged 0-14 in need of service in Victoria	Percentage of total needing service
Speech impaired	3.5%	34250	35%
Learning disabled (language-learning disabled, dyslexic, etc.)	3.0%	29357	30%
Developmentally delayed/ Intellectually disabled/ Mentally retarded/ Multiply handicapped	2.5%	24464	25%
Hearing impaired/Deaf	.5%	4892	5%
Physically impaired/ Orthopaedically handicapped	.2%	1957	2%
Visually impaired	.1%	978	1%
Behaviourally handicapped	.1%	978	1%
Emotionally handicapped	.1%	978	1%
	10.0%	97,854	100.0%

Table 1 reveals that the largest group of individuals in need of specialised services consists of those labelled 'speech impaired'. This group comprises over one-third of the entire population in need of specialised services. This group would include children who stutter, have voice problems, have difficulty pronouncing words or sounds and probably those individuals with grammatical errors etc. This group of individuals includes children labelled as language delayed, aphasic or dysphasic, specific language impairment and the like. Regardless of the label, these individuals obviously need services from qualified 'Speech Therapists' (see Parsons, 1985, for a discussion of the problems with the use of this term).

It is important to recognise that the categorical system used in Table 1 (by the Health Commission) is extremely misleading in terms of communication impairments. Every other category label utilised would include a significant proportion (above 80%) of individuals who would be in need of and/or benefit from assessment, remediation and/or overall management of their communication skills/program. For example, almost every individual labelled as 'developmentally delayed', 'intellectually disabled', 'mentally retarded', and/or 'multiply handicapped' could be expected to suffer from some sort of communication impairment. Each of these individuals or their families could benefit from services aimed at communication training. It may be instructive to note that the changing emphasis away from 'speech', to an emphasis on 'communication' by 'Speech Therapists' has been accompanied by a substantial belief that almost every 'intellectually handicapped' person can be helped in some way to communicate more effectively.

It is also now recognised that a majority of learning disabilities are communication-based problems (Ripich & Spinelli, 1985; Simon, 1985a, 1985b; Wallach & Butler, 1984). Thus, many children with learning disabilities could benefit from communication-based management. In addition, there is no doubt that hearing impaired and deaf individuals have communication difficulties and must receive appropriate assessments and interventions. Finally, numerous emotionally disturbed (possibly labelled as 'autistic', 'psychotic', 'abused' etc.), behaviourally handicapped, visually impaired/blind and physically impaired individuals (eg. cerebral palsied, etc.) may also have communication impairments requiring specialist services of a 'Speech Therapist'.

It should be obvious from the above comments that communication problems co-exist in a significant number of individuals who have a variety of types of handicaps or disabilities. Communication is a central aspect to all disabilities and is frequently cited as the major disability by many parents of handicapped children. Thus, it can be concluded that there are over 100,000 children (aged 0-14) of families in Victoria who could benefit from management of their communication programs/skills.

Although there are numerous individuals in need of assessment, remediation and/or management of their communication skills program, there is a severe shortage of professionals specifically trained to provide this service. In Victoria, there are approximately 300 'Speech Therapists' or 'Speech Pathologists' (for a discussion of their job roles, special skills and problems see Parsons, 1985). Estimates suggest that approximately 60% or 180 Victorian 'Speech Therapists' spend a majority of their time providing services to communicatively impaired children (others provide services to adult populations, are involved in administrative roles, work only part-time, etc.). This workforce of 180 would each have to manage approximately 500 individual cases in order to provide adequate coverage to the children identified as being in need of such specialised services. (Even if one were to reject earlier statements about the role of Speech Therapists in providing services to the learning disabled, intellectually disabled, hearing impaired, etc., each therapist would still need to provide services to approximately 175 individuals.) Using traditional service delivery models in the current economic situation, it is not practical or possible for Speech Therapists to assist all those in need of 'specialised services'.

It should also be noted that many of the individuals labelled 'intellectually disabled', 'learning disabled', 'hearing impaired', 'autistic', etc., will need long-term management. In addition, each year additional children will be identified (and labelled) as having those disabilities and the co-existing communication impairment. Thus, the number of individuals needing specialised services and long-term management will continue to increase. This is a particular problem in light of the fact that the number of 'Speech Therapists' in the workforce remains relatively constant from year to year. The reasons for this lack of increase in the workforce are complex but include attrition due to 'burn out' and 'poor career structure'.

The shortage of 'Speech Therapists' and the increasing number of individuals in need of services has resulted in long waiting lists at some centres which may require waits of up to two years (McAllister, 1985; Parsons, in Press) and an inability of many employing bodies and/or families with children who are suspected or known to have communication problems, to locate services. (For an in-depth discussion of possible consequences and solutions to such delays see McAllister, 1985 and Parsons, 1985.)

In order to alleviate the lack of services problem, Federal and State bodies have called for increases in the number of enrolments in 'Speech Therapy' training courses. However, many of the training schools do not have sufficient staff resources or facilities to accommodate increasing enrolment numbers. Also, this strategy of increasing enrolments may not alleviate the shortage for another 5-7 years. In addition, such a strategy may not be viable in terms of the economic situation. That is, someone will have to establish new jobs and pay these individuals for their services. The current health care model in Australia (for Speech Therapists) suggests that Federal and State bodies will have to carry the additional costs. Thus, economic factors will prevent such a strategy from being effective.

Some training bodies have begun to train teachers and/or paraprofessionals to assist in and/or provide services to the communicatively impaired. While there is ample evidence that teachers and other paraprofessionals can be highly effective in such roles, most models assume that their work would be under direction of a communication disorders specialist. It is questionable if one or two years' training in communication disorders, even with a background in education, is sufficient to adequately diagnose and design appropriate remedial programs for the broad range of communication impairments that might be found. Thus, the efficacy of such a model will need to be demonstrated. It is our opinion that there will continue to be a need for highly specialised individuals in communication disorders to provide a consultative back-up or support service to such paraprofessionals.

The Speech Therapy profession has long been aware of the lack of services and other problems with service delivery. Some of the leaders in the profession have begun to act to resolve some of the problems. One such leader, McAllister (1985) stated:

> 'There is growing public frustration at the lack of speech-language pathology services. Additionally, in some areas, there is growing discontent with the nature of speech and language services being delivered. Unless speech-language pathologists are prepared to move into a wider array of clinical settings and attempt to provide varying levels and types of services to a wider circle of client groups, dissatisfaction of this type will increase. The

> profession will find itself watching on the sidelines as other professional groups develop and offer the types of services that client groups want.' (p. 150)

McAllister (1985) goes on to point out the numerous problems related to the 'only we can do it' attitude of Speech Therapists and the traditional 'one to one' therapy delivery model. She proposes that Speech Therapists should begin to utilise groups to maximise efficiency and that a basic move to integrate Speech Therapy services into classrooms is needed. Such a model of service delivery has been shown to be successful in other countries for management of some types of communication impairments (but obviously not all types). Finally, McAllister notes (and correctly so) that parents and other paraprofessionals can be successfully utilised in the management process.

In summary, it is painfully obvious that there is a great need for additional services from highly qualified communication disorders specialists who can extend beyond the traditional therapy model. The following section describes one alternative service delivery model which is currently being utilised in Victoria and Queensland and has been adopted on a national level by The Australian Down Syndrome Association.

COMMUNICATION CAMPS

In 1982, an alternative service delivery model aimed at management of communication impairments via a consultative model was developed. This service has come to be known as 'Communication Camps'. In 1983, Bowman and Parsons reported on the 'Camp' and provided a general description of the camp goals, programs, and organisational structure. This earlier report did not address in detail the service delivery or management model aspect of the camps. Therefore, one purpose of this report is to provide details concerning the factors involved in the management process. Thus, this section has two major parts relating to assessment issues and management.

Assessment Issues and Service

Over the years, limitations of traditional assessment models have been identified by professionals (Ballard, 1983; Leonard, Prutting, Perozzi & Berkley, 1978; Messick, 1980; Muma, 1973; Muma, Lubinski & Pierce, 1982; Siegel, 1975; Stark, Tallal & Mellits, 1982) and consumers (Parsons, in Press). The common feature of these criticisms has been that traditional assessment models have not provided an accurate or useful picture of an individual's total communicative behaviour/skills. (Of course, this problem is more pronounced with individuals who have more severe communication impairments, thus these problems are not necessarily found with a child who has only a mild impairment.) One leading proponent of this view is Bronfenbrenner (1974, 1977) who commented that much of the information collected via traditional assessment approaches negated the normal or natural learning situation since therapists frequently required children to participate in activities (usually tests) which were unnatural. In addition, these activities frequently occurred in 'strange situations with strange adults for the briefest possible periods of time'. Thus, these situations placed numerous individuals at a disadvantage even before the actual 'testing' began. Bronfenbrenner concluded that assessments conducted in such a manner were 'ecologically invalid' and did not necessarily represent a particular child's 'true' ability level.

The assessment model utilised during communication camps helps to overcome these problems and is considered to be 'ecologically valid'. The camp assessment model has at least four distinct advantages over traditional assessment models. These four advantages are explained below.

First, the camp situation provides an opportunity to collect data which is natural and representative of each child's 'true' skills and abilities. Although camp may not provide an exact representation of the child's home and/or educational environment — it is a reasonable compromise. Ideally, to obtain an accurate picture of the child's skill, it would be useful to collect information in the child's home, educational environment, social environment and a clinical situation. However, the lack of specialists available, the time required and the economic considerations make such a practice almost impossible. Camps offer a quasi-naturalistic environment which can be altered to represent a 'home-like', 'school-like', 'social' and/or 'clinical' situation. Camps provide opportunities for professionals to assess each child in a variety of physically different settings (indoors, outdoors, kitchen, toilet, therapy room, etc.); in a variety of different situations (play activities, mealtime, preparing for bed, helping dad, a teaching-learning situation, interacting with peers, etc.); and in a range of structured to unstructured, formal to informal, and child oriented (or directed) to adult oriented (or directed) activities. Thus, these situations provide a broad range of behaviours to be observed. Many of the activities may be 'fun' for the children and thereby enhance motivation, relevance and meaningfulness to them. Thus, children are provided with numerous opportunities to perform at their best rather than the frequently disadvantageous test situation. In addition, children are given extended periods to 'adapt' to the situation and their potential 'assessor'. Thus, no child is penalised for 'shyness' or unwillingness or inability to participate in tests or test procedures. There is no pressure to complete a prescribed set of tests in a limited time period as usually happens in traditional assessment situations. Camp assessments occur over an extended period of time which allows for continuous behaviours to be observed. Thus, potential antecedent and consequent behaviours can be monitored. The interactive effects between the child and the extended family (including parents, siblings, peers, caregivers, teachers, other health care providers, etc.) can also be considered. Thus, the system of prevention, training, and/or communication used by these 'significant others' can be assessed and later targeted for intervention, if deemed necessary. (This may include assessing the use of modelling, prompting, cueing, shaping, feedback and reinforcement and other training techniques utilised. Such an assessment may include communicative skills and/or toileting, dressing feeding, academic skills, etc., as necessary.)

Secondly, the camp situation allows opportunities for families (and other members of the child's social system) to become actively involved in the assessment process. All families have an obvious legal right to be involved. Many families may also feel a strong personal need to be involved. From our point of view, not only do the families have a right and possibly a need to be involved, they also have valuable information which is central to assessment and program decisions. Thus, families are valuable members of the assessment team. Often family members or others who work with the child can provide insight into additional skills or talents the child may possess. They may be useful in interpreting communicative intentions of their child. In addition, they can provide relevant details concerning other services and practical limitations of programming decisions. It is critical to note that the interactions between the families and professionals will help each member of the team gain insight into the total needs, priorities, understanding of the 'problem', style of communication, style of coping, etc., which may need attention. For example, knowing how the family communicates (sends messages to others and understands or interprets messages of others) may be useful in explaining information to them. Having families available and involved (but not forced involvement) should expedite open, honest and realistic discussions. Such opportunities allow professionals to facilitate informed, group problem-solving and consensus decision making aimed at helping the total family (not just the child with the communication impairment).

A third advantage of the camp model is that it is efficient in terms of time and costs, yet allows for comprehensive evaluations to be completed. Camps allow professionals with opportunities to assess (and manage the programs of) numerous individuals concurrently, thus allowing professionals to be time and cost efficient. There is no problem with missed appointments or time lost in struggling to get a child involved in a task. In addition, individuals who have essential information are immediately available for an extended period of time. No time need be expended in making repeated telephone calls to receive information. No time is lost in having professionals make repeated visits or long trips.

As camps are usually operated on weekends (Friday afternoon to Sunday afternoon), there are approximately 30 hours available to conduct the program. (It should be noted that the camp does not need to be restricted to a weekend or to 30 hours. Some camps have been held over a four-day period. Some similar camps in the United States operate for up to 3-6 weeks in duration.) This 30 hours of program time is roughly equivalent to one full year of traditional speech therapy time (using a 10-month year with holidays, etc., at one session per week at 50 minutes per session, minus the average number of times for missed and/or cancelled appointments). Although it is not intended in this report to discuss the financial aspects of such a service, it is important to note that costs are reduced by one-third to one-half of the amount it would cost to employ a therapist.

Finally, the fourth advantage of camp assessments results from the unique philosophical orientation. The philosophical orientation is one which emphasises collecting comprehensive, systematic, 'naturalistic' (valid) and reliable information through observation, discussion and, when possible, standardised tests. Such an orientation allows for maximum flexibility and adaptation of assessment procedures to an individual's needs rather than requiring that each child conform to a testing situation. Thus, each child has numerous opportunities to demonstrate his/her 'true' ability. This orientation allows valid assessments to be completed on 'test takers' and non-test takers', verbal and non-verbal individuals, and the full range of handicapping conditions at every age and ability level.

All assessments are comprehensive and detailed. It is our view that communication is central to **all learning**. A child who cannot understand, cannot learn. A child who cannot express himself/herself verbally or non-verbally cannot demonstrate to others what has or has not been learned. We also believe that **all behaviour** (verbal and non-verbal) is potentially communicative, and thus we set out to substantiate what is intentional and what is unintentional (voluntary from involuntary). In order to encompass **all learning** and to consider **all behaviour** a transdisciplinary view is utilised.

A transdisciplinary view suggests that the professionals involved are able to cross disciplinary boundaries. This view is slightly different from an interdisciplinary view in which professionals representing numerous different disciplines might concurrently assess the child and then discuss their findings. Camp assessments are more powerful than a series of separate evaluations by different professionals. The power of transdisciplinary assessments originates from the ability of assessors to view the same set of behaviours and to evaluate the behaviours in light of educational, psychological, sociological, and communication goals and skills. What this means is that a teacher, psychologist, sociologist or speech therapist who has specialised in communication will be able to provide more insight than the assessor who has only specialised in one discipline. The ability to cross disciplines is a particularly useful skill in understanding the needs of the 'whole' child and his/her family. All supervisors (assessors) on camps have such transdisciplinary training.

In line with this transdisciplinary view, all assessments incorporate three major disciplinary views. Thus, each child's cognitive, linguistic (or sometimes called speech) and communicative-social systems are investigated. Table 2 briefly lists some of the subskills which are typically assessed. As mentioned previously, all skills are assessed by using a combination of: (1) observation (collection of behavioural and/or language samples); (2) structured and unstructured, standardised and non-standardised tests and test procedures; and (3) discussions with parents, teachers and other professionals.

Table 2. A brief list of some of the subskills which can be assessed and/or utilised when deemed necessary to make management decisions.

Skills to be assessed	How is information collected?		
	Observation (Sample)	Test Procedures and Tests	Discussion (Parental Report)
I. Cognitive System (skills)			
A. Structure and Function of neurological and sensory systems.			
1. Neurochemical and/or metabolic abnormalities (eg. epilepsy)			
2. Vision, hearing, etc. (structure and function)			
3. Physical abilities (eg. motor skills) (structure and function)			
4. Oral peripheral mechanism			
B. Development learning behaviours/ skills			
1. Motivation/Exploration/Play/ Attention			
2. Imitation/Modelling			
3. Means end/Anticipation/ Casuality/Object performance			
4. Symbolic representation			
5. Memory and retention of information (verbal and non-verbal)			
6. Descrimination/Matching/ Visuospatial/Categorisation			
7. Problem solving			
8. Metacognition/Metamemory			

Skills to be assessed	How is information collected?		
	Observation (Sample)	Test Procedures and Tests	Discussion (Parental Report)
C. Individual learning styles/ strategies (eg. verbal vs non-verbal learner; impulsive vs reflective; field dependent vs field independent; memorisor vs integrator; spatial vs verbal learner; analytic vs gestalt thinker; systematic vs intuitive thinker; constructively vs defensively motivated; patterners vs dramatists; conservative vs risk taker; imitator vs non-imitator; test taker vs non-test taker; etc.)			
D. Rate of learning/Amount of learning/Preferences/Potential			
E. Special talents or skills			
II. Linguistic System (skills)			
A. Understanding and use of semantic skills (ie. concepts, words, and word combinations)			
B. Understanding and use of grammar (syntax & morphology) (ie. grammatical forms; correctness or grammar or types of errors; combinations of errors)			
C. Articulation/Phonologic/ Pronunciation skills (ie. ability to make sounds, types of consonants and vowels used; syllabic structure used, processes affecting 'intelligibility'; etc.)			
D. Voice (ie. loudness, quality, pitch etc. and ability to alter these aspects to meet situational requirements)			
E. Fluency/Stuttering and Rate (ie. types of disfluencies; where they occur; when they occur; child's reaction to them; others' reaction to them; associated maladaptive behaviours; rate, too fast or too slow)			
F. Special 'Verbal' Behaviours (eg. only a few vocalisations used; whistling; singing; echolalia; stereotyped utterances)			

Skills to be assessed	How is information collected?		
	Observation (Sample)	Test Procedures and Tests	Discussion (Parental Report)
III. Communicative — Social System (skills)			
A. Intentional communication which may be non-verbal gestures or sugnes, noises, words, sentences, echolalia, stereotyped responses or combinations of these behaviours.			
B. Purpose of communication attempts (functions). (eg. requests objects, requests action/help, requests information, greets or attracts attention, protests, labels, answers, acknowledges, gives information, commands, practice for self-stimulation or fun, threatens, repeats to guide actions/behaviours, showing off, express pleasure, express affection, show ownership, etc.)			
C. Conversational skills (eg. ability to: attend, listen, make assumptions about what listeners know, select appropriate topics, initiate conversations, provide relevant information, ask for more information, ask and respond to questions, ask for assistance, stay on topic, change topics, ignore criticism, refuse to comply with others' requests, participate in simultaneous topics of conversation, take conversational turns, terminate conversations, use correct intonation, use politeness, shift or alter style of communication depending on listener needs, highlight importance of needs, compromise and negotiate, provide rationale for decisions, tell jokes, create stories, etc.)			
D. Understanding and use of gesture (eg. maintaining eye contact, use of proximity, posture, facial expressions, non-verbal active listening skills, like smiling, nodding, etc.)			
E. Understanding and use of augmentative systems (eg. sign language, communication boards, etc.)			

Skills to be assessed	How is information collected?		
	Observation (Sample)	Test Procedures and Tests	Discussion (Parental Report)
F. Communicative failure (eg. What does child do if listener doesn't understand or respond? Does child attempt to communicate again? Does the child change (correct, revise, repair or ask questions) some aspect of communication to help the listener understand? Does the child have tantrums or fail to try again? Does the child tell others when he/she doesn't understand? How? etc.)			
G. Contextual/Interactional skills (eg. Does child seek out or avoid particular activities or individuals? Do communicative behaviours change with different listeners, situations, settings? How do others attempt to communicate with the child, etc?)			
H. Behavioural/Educational/Vocational/Social skills.			
1. Self-help (toileting, dressing, eating, etc.)			
2. Tantrums, self-abusive, and/or aggressive behaviours			
3. Repetitive, stereotyped maladaptive behaviours			
4. Academic (reading, writing, narrative skills, maths, spelling, etc.)			
5. Special talents, particular likes and possible vocational prospects			
6. Social skills (leisure time — hobbies, dating, etc.; living and working with others; social etiquette; helping out with house cleaning; budgeting, shopping, participation in group activities or programs, etc.)			

Skills to be assessed	How is information collected?		
	Observation (Sample)	Test Procedures and Tests	Discussion (Parental Report)
IV. Assessment of progress over time/ Evaluating effectiveness			
A. Child's progress (as determined by parents, teachers & independent assessors)			
B. Satisfaction of parents, child and others with progress			
C. Potential problems identified and 'corrected'			
D. Determination of needed new services or alternative services/ placements			
E. Re-assessment of goals and expectations			
F. Data-based decision making			

For every subskill listed in Table 2, a set of observation protocols, tests and test procedures, and a series of questions for 'others' have been established. This format has come to be known as the Parsons Assessment Procedure (PAP). This procedure does not imply that every child must take every test. Such a procedure was established to: (1) ensure that each area or subskill was assessed and points out that there are three levels of conducting the assessment (ie. observation, tests, discussion); (2) standardise the assessment routine to assist assessors so not waste time in selecting what to observe, tests to utilise or questions to ask; and (3) standardise the assessment routine for comparison from one year to the next or across groups. However, it should be noted that additional tests may be utilised. Finally, all assessors have a series of questions they address in selecting to utilise any of the procedures above. These questions include : What procedures are of the highest priority? Is this procedure being done to be comprehensive or is there a real need for it? How can the procedure or test be adapted to the child without violating basic principles of validity? What sequence of testing is appropriate to this child? What desirable/undesirable consequences may this procedure create? Will this procedure give direct intervention implications? Every test and procedure must have a rationale.

In summary, the camp situation and the unique philosophical assessment orientation utilised provide a more complete and accurate picture of what skills the child has and how he/she utilises those skills. Thus, it is felt that camps provide a more 'ecologically valid' approach to assessment that traditional approaches.

Although numerous families attend camps to receive these very complete and extensive assessments, it must be noted from our point of view that the assessments are only part, albeit an integral one, of the management/intervention process. Therefore, in the next section we review the major purpose or goal of the camps — the management process.

The Management Process

In this section, we discuss : (1) the role of assessment in management; (2) particular philosophical orientations utilised on our camps; and (3) some management and/or intervention techniques utilised.

The primary purpose of assessments on camps is to assist in making management decisions. Assessments conducted without management follow-through would be unethical. On the other hand, specific management decisions made without detailed assessment information would also be unethical. Thus, the assessments are viewed as a means to an end. That end is to assist families in making management decisions. Thus, asessment information is used to : (1) act as a baseline level of performance; (2) identify treatment priorities; (3) establish training goals; and (4) when appropriate, to evaluate the extent an intervention program has benefitted an individual, thus recommendations, continued work and/or program changes may be made.

There has been some confusion concerning the management function of the camps. Some individuals have had the mistaken belief that the primary role of communication camps has been to assess children. As stated above, this is only a part of the management process. This confusion has been created by a number of factors which need clarification.

The unique organisational structure and job roles of staff sometimes mislead the casual or uninformed observer to believe that assessment is the primary aim of camps. For each family who attends camp, two undergraduate students in 'Speech Pathology' are assigned to assist a clinical supervisor in assessing the communicatively impaired child. The students spend a majority of their time observing, collecting, transcribing and analysing data. To the casual observer a great deal of time is spent in these activities. Thus, assessment is viewed, whereas management is not. These students fulfil a technical role (some parents have fulfilled the same role on camps). However, the clinical supervisors are responsible for management. They may have spent less time in actual contact with the child, but they have access to all the data. Ultimately, they are responsible for analysing and interpreting all the information collected and making management recommendations which are meaningful, positive, preventative and/or remedial which integrate the total communicative needs of the child and his/her family with the child's overall educational, vocational, behavioural and/or social program.

In order to fulfil their unique management role, clinical supervisors are highly qualified and dedicated individuals. Each one has : (1) specialised in some area of communication disorders; (2) had post-graduate training; (3) had extensive practical experience; (4) a transdisciplinary view (with many having completed a second qualification in a second discipline, ie. communication disorders, education, psychology, sociology, hearing impairment, learning disabilities, etc.); and (5) a commitment to a consultative service delivery model. Thus, these staff members are the key to the success of the management aspect of the camp program. Although their role is most crucial to the success of the camp, the work they do is not directly observable and the management discussions with the family usually take place on the final day of the camp and last about two hours. Thus, many families have believed that management has been downplayed or receives less emphasis than assessment. However, our feeling is that a consultative management model typically works in this manner and families must come to recognise the difference between a management service and direct intervention service.

A direct service delivery system has traditionally assumed that the individual who does the assessment will also do the intervention with the child. Also, many consumers believe that their children need 1:1 service delivery. However, given the earlier arguments about the lack of qualified personnel and the limited amount of funds available, the consultative service is a viable option. There are numerous reports of successful consultative services.

Although there are a variety of consultative models (for a review of some types see Frassinelli, Superior and Meyers, 1983), the one utilised on camps emphasises: (1) collaboration between all those involved with the child to jointly problem solve; (2) a periodic contact, usually every one or two years; (3) group assessment and management discussions; and (4) intervention approaches which are implemented by other persons (eg. professionals, teachers, perents, etc.). Certainly it makes good sense to utilise the services and skills of teachers and/or parents who frequently are already competent (and available) to develop communication skills in their children. In addition, there is voluminous evidence available to demonstrate that parents and other paraprofessionals can effectively change communication behaviours of their children (ASHA, 1979; Hall & Knutson, 1978; Scalero & Eskenazi, 1976; Shinn-Stricker, 1984).

As part of the management/intervention process, a series of techniques are utilised to assist families in management. First, a series of workshops or seminars are provided for families. These programs occur simultaneously or concurrently while the student workers (and often the clinical supervisors) are assessing the children. These sessions attempt to inform families about: a) communication development, b) communication disorders — their possible causes, effects on learning, etc., c) assessment procedures, processes and tests, d) intervention types — advantages and disadvantages, and e) where and how to locate and work effectively with professionals. These workshops and seminars are conducted by PhD level staff or other highly qualified individuals. Sometimes important issues are raised before camp which may require workshops from other professionals (eg. psychologists, occupational therapists, physiotherapists, social workers, teachers, doctors, etc.) who are then invited to participate.

Secondly, a problem-solving format is utilised in discussions with families. Parents are asked to: a) identify problems, b) define the problems, c) prioritise the problems, d) explore possible alternative ways of dealing with each problem and identify the potential advantages and disadvantages of each alternative, e) attempt a solution by doing something and f) evaluate the effects of the attempted solution [e) and f) usually entail role-playing activities during sessions]. By utilising this problem-solving format, it is felt that some families will learn how to systematically work through problems. This technique can also help to reduce dependency on professionals.

The third management technique, and probably the major one, used on camp is the consulting session. These sessions typically occur on the final day of camp and last approximately two hours. During these sessions, the student workers and clinical supervisors meet with family members to discuss their findings. During the session all data is reviewed and summarised for the family. Once an agreement is reached that the assessment has been representative of the child's abilities a discussion of the current services, needs, problems and progress takes place. A series of recommendations are agreed upon for short-term and long-term management. A comprehensive (typed) report which provides an in-depth summary of the assessment findings and a listing of all agreed upon recommendations is sent to the families. Families are encouraged to distribute the report as they feel appropriate.

Since systematic, comprehensive, reliable and valid data are collected on each child, data can be used over time to make decisions about efficacy of services. This information allows camp staff to assess overall progress and to plan optimal treatment programs.

In evaluating program effectiveness, we ask the following questions:

a) Has the child progressed? According to our independent assessment, parental views and those involved in the program (training)?

b) Are the parents and program staff satisfied with the amount of progress?

c) Are the areas of improvement those 'targeted' as high priority for the child?

d) Is the child suffering from any stress, are other behaviours deteriorating, etc.? (We frequently ask, 'does the child like to go to school, Speech Therapy, etc.?')

e) Is there any unnecessary stress or strain on the family emotionally, economically, time-wise to obtain this service?

When families are not satisfied with a service, a problem-solving technique is then involved to review potential alternatives and possible outcomes. Families are also reminded of 'the grass always **looks** greener on the other side' phenomenon and are asked to consider program changes carefully. When a program has been shown to result in positive changes in behaviour, appropriate feedback is given to all those involved.

A fourth technique sometimes utilised during the camp is the actual training of a parent in a particular intervention task. Usually, this takes the form of: a) the clinical supervisor demonstrating (or modelling) a specific technique for the parent to observe, b) allowing the parent to practise the technique while the clinical supervisor observes, c) providing immediate and specific feedback to the parents about their use of the technique with the child, and d) having a discussion with parents about issues of generalisation (usually taking a problem-solving orientation).

A fifth management service, which usually occurs after camp, is the use of bibliotherapy. Bibliotherapy is simply providing a reading list or series of articles, book chapters or books to families (or teachers). These readings are usually directly related to a specific question which has been raised on camp or may provide general information to the family. Bibliotherapy has been shown to be of some value in helping families to actually change behaviour. However, it assists more in helping families to understand and cope with their child's problem, as well as feel that they are not isolated, and assists them in making informed decisions.

A sixth management service provided is the option for follow-up or continued consulting. This service is offered by camp co-ordinators and is felt to be a critical component of the camp's management service. Families are advised that telephone conferencing or consulting is available if it is deemed necessary. Occasionally, visits to schools or homes are necessary to conduct further assessments, inform others concerning findings on camp, train others in specific techniques, and/or to assure that proper training techniques are being utilised. Sometimes this follow-up service requires us to locate services for a family or act as a child advocate or help to negotiate details of service in a particular school. Frequently families send in transcripts of language samples, audiotapes or videotapes for continued contact. Attempts are made to respond to all these needs. Finally, it should be mentioned that some families are contacted to participate in clinical research projects. In return for their participation they may receive intervention and/or continued consulting depending on the nature of the project. It should be noted, however, that no on-going intervention is implied by participation on camp. Resources for intensive communication therapy provided by professionals are not available. Indeed, there are some efforts by administrators to limit even our consulting contact with families. However, when our follow-up is restricted, the question of ethics of the service can then be raised, as we would be offering primarily an assessment service.

A seventh service utilised is through continued effort to train groups of parents to conduct intervention via Lincoln Institute Continuing Education programs and the Human Resource Centre at LaTrobe University. Families who have attended a camp are added to mailing lists which announce these workshops or courses.

In summary, a variety of management/intervention techniques associated with communication camps have been identified. The full potential of this alternative service delivery model is realised when families attend camps on a regular basis (minimally one per year or every two years). It assumes that others will do the direct intervention work and that competent consulting will help the family to make informed decisions which will lead to maximum benefits to their communicatively impaired child. Finally, it should be stressed that this service can be a viable service for families who do not have ready access to professionals or a complementary service to families who have ready access to services but would like a second opinion. This form of service optimises the use resources without placing undue stress on families or professionals.

Participants

This section will describe the individuals who have thus far participated in camps, and point out future plans.

Over the past six years, 170 different families have participated. Of these, 126 have attended one camp, 32 two camps, 9 three camps, 1 four camps and 2 families attended each year for 5 years. A majority of families have come from Victoria, however, families from New South Wales, the Northern Territory, Queensland and South Australia have attended. One family flew in from Iraq in 1983.

Although we do not like to utilise labels which might lead to negative connotations, and we recognise that labels do not represent individuals, it is necessary to provide readers with an overview of the type of children who have participated in this service. Since there is a great deal of overlap and confusion among labels we differentiate language impaired, articulation impaired, intellectually disabled, Down Syndrome and autistic individuals. The category an individual child is placed in is determined by professional reports, the labels utilised by parents at the first camp, and results of our assessments. Table 3 demonstrates the labels used for the children who have been involved in camps and the number of children in each category.

Table 3. The number of, and primary label used to describe, children who have attended communication camps.

Language Impaired	Articulation Impaired	Intellectually Disabled (Non-Down)	Down Syndrome	Autistic
41	23	22	54	29

The term 'language impaired' is used here to include any child with the following labels: 'at-risk', 'language delayed', 'language disordered', 'aphasic/dysphasic and/or 'learning disabled'. This group excludes any children whose primary problem was with articulation or labelled as intellectually disabled, Down Syndrome, or autistic. Table 4 shows the age range and approximate distribution of labels for this group.

Table 4. Age range and approximate distribution by label of language impaired children.

		(Aphasic/Dysphasic)					
At Risk		Language Delayed		Language Disordered		Learning Disabled	
1:8	4:1	5:0	6:2	7:2	8:4	9:0	11:6
2:0	4:4	5:0	6:4	7:4	8:5	9:5	11:10
2:4	4:6	5:2	6:5	7:7	8:7	9:9	11:11
2:7	4:7	5:4	6:6	7:10	8:10	9:11	12:5
2:9		5:6	6:6			10:0	12:9
3:1		5:6					
		5:8					
		5:11					

It is important to note that chronological age and severity of 'delay' or type of impairment contributed to these labels.

The second group identified in Table 3 are the 23 articulation impaired individuals. These children have been labelled as 'articulation delayed', 'articulation disordered', 'multiply articulatorily disordered/impaired', 'developmentally dyspraxic' or simply 'unintelligible'. These labels were frequently based on age and severity of involvement. None of these children was labelled as intellectually disabled, Down Syndrome or autistic. Ages of this group ranged from 2;2 to 12;4.

The 22 intellectually disabled (non-Down and non-autistic) have been labelled as any of the following: 'mentally retarded', 'minimally brain damaged', 'epileptic', 'low IQ', etc. It is interesting to note that this group has been different from the other groups on one factor — age. The age range has been 4;10 — 16;2 with the average age of 8;7. All other groups have included children aged 3 or 4 years (or younger) whereas the intellectually disabled group has predominantly been children aged 6-12 years. This seems to indicate (and confirms previous reports) that many of these children are not diagnosed until school years. This is in stark contrast to the next group of Down Syndrome individuals.

Fifty-four individuals with Down Syndrome have attended camps. Although many of these individuals have been labelled as 'intellectually disabled' we did not accept this as a given fact, so we created this special listing for them. Many of these individuals had language and/or articulation problems, but we felt it was necessary for readers to recognise that communication camps are available to individuals with Down Syndrome. The age range has been 3;0 — 17;8 with an average age of 5;4.

The last group of 29 individuals has been labelled 'autistic' or 'autistic-like'. Many of these children have also been labelled as intellectually disabled and/or language disordered, but for our purposes were placed only in this category. The age range of these children has been 3;5 to 18;9 with a median age of 6;6.

Since we have attempted to categorise the type of individuals who have attended, it may be useful to note that we have not had individuals whose primary disability has been labelled as: 'hearing impaired or deaf', 'visually impaired or blind', 'cerebal palsied', 'cleft palate', 'stutterers' or 'voice problems'. Nor have we had individuals who have had strokes or received head injuries. However, individuals with any or all of these problems could benefit from camp assessments and consultative management.

The entire point of this review has been to demonstrate that assessment/management of any individual — with any label or etiology, at any age level and of any severity — can be completed. Thus, no individual needs to be without access to professional consultative services. Similar opportunities could be made available to other groups who felt that such a service would be useful.

The Future

Evaluations concerning the camp program are conducted systematically by independent evaluators. Feedback is routinely solicited from all families. Thus far, evaluations and feedback suggest this model is a much needed, well-received, and integral part of the services for many families. It is hoped in future reports detailed evaluation data can be reported concerning consumer satisfaction and actual changes in behaviour which may occur as part of the program.

All of the data collected on children are kept for research purposes. When a large enough sample has been collected a series of clinically relevant questions may be able to be answered.

Finally, it is hoped the future will see a permanent communication camp setting to be utilised by all Australians with communicatively impaired children to serve as a central location for families unable to receive services elsewhere. Failing a permanent camp site, efforts are currently underway by the authors, in conjunction with Lions Clubs of Australia to offer week-long (5 day) communication intervention camps. The first such camp was held in August 1987 at Camp Licola for 'speech and language impaired' children. This camp provided treatment centred on recreational activities. The children who attended this camp received the equivalent of one full year of traditional 'speech therapy'. In October 1987, the Australian Down Syndrome Association identified the communication camps as one of their highest priorities with the goal of providing each state and territory with access to similar camps. For those families who live in remove areas of Australia, attempts are being made to provide similar services via the use of a full range of telecommunication systems like audiocassettes, video cassettes, two-way telephone systems, computers, videodiscs and the AUSSAT satellite (Parsons & Smale, 1988), to mention a few. Thus, our efforts to offer high quality alternative forms of service delivery continue. Who knows what the future will hold?

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Chapter 18

LEARNING HOW TO DEAL WITH LEARNING DIFFICULTIES: THE EXCEPTIONAL CHILDREN'S UNIT AT THE UNIVERSITY OF WESTERN AUSTRALIA

Chris Pratt
Robert Grieve

When children encounter learning difficulties due to mental, physical, or multiple handicaps, it is important that their problems are identified early; that they are provided with appropriate assistance designed to reduce or overcome their difficulties; and that there is an appropriate educational provision with trained staff for these children. Recognition of the importance of these factors, and of difficulties that may be encountered in achieving them, led to the establishment of a Unit for Exceptional Children at The University of Western Australia some ten years ago (Little, 1978).

At that time, difficulties arising from two main sources were being experienced in the provision of assistance for, and the appropriate placement of, preschool children with learning difficulties. First, many of the agencies involved with young children were placing in a normal preschool setting those who, because of the nature or severity of their handicap, would not benefit from such placement without appropriate intervention and additional assistance being available. This problem arose either as a result of a lack of understanding of the educational philosophy and programs involved in preschool education, or because the person making the referral had insufficient opportunity to carry out more than a routine assessment and could not be aware of how a particular child might function in a preschool setting. Second, many preschool teachers and teacher aides had little experience with handicapped children and, more importantly, were inexperienced in appropriate programming and management techniques for working with special children in integrated educational settings. As a result, several difficulties could arise. Some teachers and aides might spend too much time with a handicapped child in their group and, consequently, the overall program would suffer. Other teachers might largely ignore the handicapped child through a lack of confidence in working with such children. It was evident, therefore, that a special provision was required which would provide appropriate early intervention for children with handicaps. It also needed to address the difficulties that were being encountered generally, through inappropriate placements and a lack of staff with experience in educating children with handicaps. Consequently The Exceptional Children's Unit was established.

The founding Director of the Unit was Dr Audrey Little. She was succeeded, first by Dr Robert Grieve, then by Dr Chris Pratt who is currently Director of the Unit. The Director, through holding a full-time academic appointment in the Department of Psychology at the University of Western Australia, is, like all University academic staff, involved in research and in teaching undergraduate and postgraduate students. An important result of this circumstance is that the Exceptional Children's Unit is not simply involved with children being helped to learn how to deal with their learning difficulties. The process of learning is in fact much wider, and involves children, their parents, professional teachers and therapists, undergraduate and postgraduate students, and University staff. These different groups of individuals are involved in learning about learning difficulties in a variety of ways, as will be described. However, it is first necessary to indicate the general context in which the Exceptional Children's Unit is set — that of the Child Study Centre.

CHILD STUDY CENTRE

The Child Study Centre, part of the Department of Psychology at The University of Western Australia, is located on the University campus. Its main facilities for children consist of three kindergarten units — one for 4-year-olds; one for 5-year-olds; and one for handicapped children enrolled in the Exceptional Children's Unit. The facility was custom-built for children, and for University teaching and research. There are therefore child-sized cloakroom and washing facilities, indoor and outdoor areas, and plenty of activities and equipment to help encourage the learning and development of preschool-aged children. In addition, there are observation booths with one-way viewing screens and audio and video facilities so that staff and students may study children without distracting them, and additional test, observation, and therapy rooms in the Centre allow children to be studied individually or in small groups. Each kindergarten area is staffed by a qualified preschool teacher and aide. There are seven groups of children who attend the different kindergartens on a sessional basis. The maximum number in each of the two groups who attend the 5-year-old unit is 25, while in each of the three groups of 4-year-olds, the maximum number is 20. There are two groups of eight handicapped children in the Exceptional Children's Unit.

This information will indicate that the Exceptional Children's Unit does not operate as an isolated group of handicapped children. Rather, it is set in a noisy, bustling, and active context, where there are many preschool-aged children, some of whose development is proceeding normally, and others whose development is atypical. The course of development of these various children is constantly being studied, both to train students, and to obtain a better general understanding of how children may grow, learn, and develop.

Having the Exceptional Children's Unit set in the larger context of the Child Study Centre brings two distinct advantages. First, learning difficulties are not considered in isolation from the normal course of learning and development, for the latter is readily apparent in the mainstream 4-and 5-year-old groups. Second, as will be considered further below, having groups of normal and handicapped children in the same Centre greatly facilitates the process of integrating handicapped children into mainstream kindergartens.

EXCEPTIONAL CHILDREN'S UNIT

The Unit is funded by the State's Education Department, the State's Health Department, and by the University. The Education Department provides a qualified preschool teacher with special training in learning difficulties, a psychologist, a part-time teacher's aide, and a part-time secretary. The University provides and maintains accommodation and equipment, and the Director who is a member of the full-time academic staff and is responsible for the activities of the Unit. A speech therapist from the Health Department also attends the Unit for three sessions each week.

The Unit is attended by two groups of children in the 3- to 5-year-old age range with one group attending for three and the other for two morning sessions per week. They are mainly referred to the Unit by psychologists and medical practitioners at various agencies concerned with preschool children in Western Australia (eg., the Child Development Centre; Princess Margaret Hospital for Children).

All have a handicap or behavioural problem likely to result in their experiencing some learning difficulty in preschool or primary school, including mild or moderate intellectual handicap, brain damage, physical handicap, language and communication disorders, and social, emotional and behavioural problems. Children identified as having handicaps which are severe are not enrolled at the Unit, for it does not have the facilities needed to cater for these children.

For children attending the Unit, four interrelated aspects of educational provision are emphasised; these concern the educational program for each child; the integration of children in the Unit into the mainstream 4- and 5-year-old kindergarten groups; the on-going assessment of children in an educational setting; and the involvement and counselling of parents. These aspects can now be considered in turn.

1. Individual Educational Programs. Educational programming for the children involves a team approach, with the teacher assuming overall responsibility for all aspects of each child's program, while the psychologist and speech therapist provide detailed input, both on general issues and on specific programs for individual children. The programming combines aspects of the developmental approach adopted in most preschool situations with detailed specific intervention programs designed for individual children. There are three main aspects to the program.

1. Like all young people, children in the Unit need to be treated as individuals, and their linguistic, intellectual, perceptual, physical, emotional, and social development needs to be stimulated and encouraged.
2. Children in the Unit require specific intervention programs designed on an individual basis, and addressed to particular individual problems or difficulties.
3. Since a basic aim of the Unit's work is to see children proceed to other educational settings, there is a need to provide children with knowledge and experience of how to operate socially in an educational setting.

These three aspects are reflected in the timetabling of activities. Children first spend about an hour in the indoor playroom, largely working on individual programs. This is followed by a group session (15 minutes) where children have fruit and a drink. There is then an outdoor play session (45 minutes) where children from the mainstream 4- or 5-year-old group are often present. Finally, there is a further group session (15 minutes) for stories or music. During these sessions, social, detailed programs may be implemented on a one-to-one basis within the kindergarten, or in a separate therapy room by withdrawing the child from the kindergarten for a short period of time.

In addition to day-to-day programming, a weekly programming session is attended by all staff. This meeting evaluates both the extent to which the goals of individual programs have been attained, and the balance between the general encouragement of development and specific intervention programs. Appropriate programs for integrating individual children into the mainstream kindergartens are also discussed at such meetings. Evaluation which is conducted within the Unit with a view to future programming, focuses both on the child's abilities, and on the extent to which the intervention program has been successfully implemented. Depending on the outcome of the evaluation, programs are continued, or modified in light of the child's progress, or modified to account for any unforeseen difficulties that might have arisen.

2. **Integration of Individual Children**. There are two ways in which integration may occur. The first is the general integration that occurs during the daily outdoor play sessions attended by children in the Unit and by children from the mainstream kindergartens. The second is the partial or total integration of individual children into one of the mainstream kindergarten groups at the Child Study Centre.

Regarding the former, while integration is actively encouraged during outdoor play sessions, the extent to which it results in interaction between the groups of children depends on the particular children involved, and the activities they choose to pursue. For example, while children from the Unit may interact with children from a mainstream group in feeding the guinea pigs, playing in the tree house, exercising on the climbing frame, or whatever, interaction may be minimal or non-existent if children from a mainstream group choose to play a fast-moving and complicated fantasy game — where the tree-house becomes, say, a different galaxy. Children from the Unit find it hard or impossible to participate in elaborate fantasy play. Interaction then recedes, and integration does not occur. Nevertheless, even when social mixing and the sharing of activities is at a minimum, benefits can still occur, such as raised level of awareness and an increased acceptance in all children of the different range of abilities amongst their peers.

Partial or total integration occurs when a child from the Unit is considered by the staff to be ready for integration into a mainstream kindergarten group. The teacher and aide in the mainstream group are first consulted and briefed, and the strengths and weaknesses of the particular child from the Unit are considered and discussed. A program for integration is then devised by the staff from the Unit and the mainstream group.

In most cases children from the Unit are partially integrated initially, spending relatively short periods of time in the mainstream group. Such partial integration is focused on the particular strengths of the child being integrated, to enhance the likelihood of success. For example, if the child being integrated has reasonably well-developed fine motor skills, then that child will first be integrated when the mainstream children are involved in activities that require such skills — eg., cutting and pasting, colouring shapes, or threading beads to make necklaces. These activities will have been planned jointly by the teacher from the Unit and the teacher from the mainstream group. Alternatively, if the child to be integrated has strengths in following stories during large group mat sessions, then the child's partial integration will be initially introduced at 'mat time', when the mainstream group is being told a story.

The integration programs of individual children are monitored by staff from the Exceptional Children's Unit and the mainstream kindergarten involved. Depending on progress, children may remain on a partial integration program or move to complete integration. When they reach the stage of complete integration, children remain at the Centre in a 4- or 5-year-old mainstream group, or move to a different kindergarten nearer the family home. Depending on the degree and type of handicap, and the progress children make, some will proceed to a special educational facility, or to a primary school where there is a special education support unit.

3. **Assessment for Educational Placement.** Making decisions about appropriate educational placement for young children with handicaps is often found difficult, even by experienced professionals. This arises because many professionals involved with young handicapped children are not trained to work with children in educational settings and may be inexperienced in matching children to the range and types of educational provision that are available. Also, assessment of a child's abilities and limitations conducted in relatively brief sessions in clinic or hospital settings may not be adequate. A more extended opportunity to assess the child in an educational environment is often required if the child's skills and limitations are to be appropriately matched to subsequent educational placement.

The Exceptional Children's Unit provides the opportunity for children to be assessed over a longer period of time, and in a preschool educational context. This allows staff to assess the extent to which each child adapts to a preschool setting generally and responds to particular intervention programs. The most appropriate educational setting for each child may then be determined in a context where there are no set expectations in terms of how long a child attends the Unit, or in terms of where the child will be placed once he or she leaves the Unit.

Each child is accepted into the program for an initial period of six weeks. During this time parent interviews are held, the child is observed in the kindergarten setting and, if appropriate, a formal psychological assessment is carried out. At the end of this period a recommendation is made to the parents about the child. This may involve the child continuing in the Unit for further monitoring and skill development, or moving to a mainstream preschool setting or other education setting that caters specifically for the type of handicap that the child has. The recommendation, along with the reasons for it, is fully discussed with the parents and a final decision made.

The length of time that children may remain in the Unit varies considerably, from six weeks to periods of over one year. This tends to avoid, or at least greatly reduce, inappropriate placement in a subsequent educational setting because of lack of knowledge about the child. Furthermore, recommendations about suitable placements are made by professionals with extensive experience of the different types of educational provision that are available. For children who attend the Unit beyond the initial period, assessment continues in parallel with the provision of an appropriate educational program and provides a basis for considering the effectiveness of particular programs and for determining when it is appropriate for the child to begin an integration program or move to another education facility.

4. **Parent Involvement and Counselling.** The amount of parent involvement in the Unit's kindergarten sessions is less than one would find in many other preschool groups (where at least one parent is usually on roster duty each session). There are several reasons for this.

1. Although the general program follows a preschool type model, the children are also on individual programs during part or most of each session. Implementing such programs requires specialist training, at least in the first instance.
2. Through the participation of inservice teachers and students (see below) there exists a favourable adult to child ratio in the Unit. The involvement of more adults — parents — would interfere with the goals of the general program by creating an undesirable adult to child ratio.
3. In some cases, parent interactions with their children are found to be inappropriate. This can arise because previous parent-child interaction has led to emotional and/or behavioural problems, or because the normal interactional processes that would develop between parent and child have not done so as a result of the child's handicap.

For the above reasons, rather than involve parents routinely on a roster basis, parent involvement is encouraged in other ways. For example, the existence of viewing facilities through a one-way observation screen provides the opportunity for parents to observe their child in the preschool setting without being in the kindergarten. This provides the opportunity for parents to observe how their child interacts with other adults and children, and how the staff work with their child. In some instances, the psychologist or speech therapist will sit in with the parents, and help focus their attention on aspects of their child's behaviour or on appropriate strategies being used by the teacher when interacting with their child. Alternatively, a staff member may work with the parent and child in a separate room. In this case, the child is withdrawn from the group, and the staff member works with the child to demonstrate a program to the parent who may then practise implementing it with the child while feedback is given. Once the parent is carrying out the program correctly, this can then be continued with the child at home.

In addition to parent involvement in their children's education, the psychologist is also extensively involved in parent counselling. The purpose of this counselling varies, depending on the individual needs of particular parents, and includes family therapy sessions, required as a result of general difficulties in the family situation, and more specific counselling to assist parents come to terms with having a handicapped child. This latter issue can of course present significant problems both for parents and their children, and at times a definite refusal by parents to acknowledge problems may interfere with the process of providing children with the most appropriate educational programs.

Through these types of involvement and counselling, parents are engaged in learning about themselves and their children, particularly with a view to learning how to encourage and assist their children's progress.

TEACHER TRAINING

An important part of the work of the Exceptional Children's Unit concerns the inservice training of preschool teachers. While their preservice training may make some reference to children whose development is atypical, the great majority of preschool teachers have little direct experience of handicapped children. The Education Department had the foresight to recognise over ten years ago that to integrate handicapped children successfully into mainstream educational settings, appropriate inservice training needs to be provided for teachers, so that they can not only learn about handicapped children, but also gain direct experience of working with them under expert guidance. Therefore each year, three inservice teacher training courses are organised at the Exceptional Children's Unit. Each course is attended by four preschool teachers, who are replaced in their own kindergartens by temporary staff. During the past ten years, approximately 120 preschool teachers have received a training in the integration of handicapped children and in working with these children generally. This has helped the State's policy of normalisation to be implemented in a realistic manner.

An inservice course lasts for ten weeks. The course is organised by the Unit's psychologist, who acts as course tutor and works in consultation with the Unit's Director. The main purpose of the course is to provide qualified preschool teachers with additional knowledge of, and direct practical experience of working with, children with special educational needs resulting from a wide range of handicaps.

Within the course, morning sessions at the Unit are mostly involved with practical work, while afternoon sessions mostly involve course work. During morning session, two of the four inservice teachers are assigned to work with children in the Unit. Their time is divided between providing general supervision and assistance, and implementing specific programs with individual children. The other two inservice teachers are meanwhile involved either in an integration program with a child, in observing individual children, or in private study. A roster system operates to ensure that, for each teacher, there is a balance between involvement in the Unit, integration programs, observation and private study.

The afternoon sessions involve course work, provided by the Unit's psychologist, the Unit's Director, the speech therapist and by invited speakers from within the University and from agencies in Perth. The course emphasises the importance of both research and practice. It covers recent research developments in the study of normal and handicapped children, and examines issues central to special education. Instruction is also provided in programming for children with special needs, including identification of specific goals, setting out a program to achieve these goals, implementing the program, and evaluating its effectiveness. Instruction also includes the appropriate use of teacher assessment, and each participant in the course is required to carry out a case study of one child and present this to the group. Finally, an important part of the course is the group project, where the four inservice teachers work together to produce a booklet. This may be a resource booklet of strategies for the integration of handicapped children, or a booklet providing guidelines for the development and evaluation of individual programs.

As the course involves working with children in the Exceptional Children's Unit kindergarten groups, and in integrated settings in the mainstream kindergartens, there is ample opportunity for the inservice teachers to apply in practical ways the knowledge they gain in private study, seminars and tutorials. While there is no formal assessment such as tests or examinations, the inservice teachers are given constant feedback on their work with the children, and on their contributions to the tutorial and seminar groups. Teachers are thereby informed of their level of performance.

Generally, the course makes an important contribution to preschool teachers' understanding of children, particularly of handicapped children, and also provides them with an opportunity to increase their skills in these areas. By learning about learning difficulties in the theoretical and practical ways described, inservice trained teachers can subsequently contribute significantly to the process of assisting children with special educational needs.

FURTHER PROFESSIONAL DEVELOPMENT

It will be evident that a significant aspect of the work of the Exceptional Children's Unit involves professional development. While this encompasses the professional development of teachers on inservice training courses as indicated in the previous section, the work of the Unit also contributes to the development of other professionals. This involves the Director, psychologist, teacher and aide of the Unit itself; other academic staff in the Department of Psychology; the teachers and aides of the mainstream kindergarten groups; and the speech therapists. As a team approach is followed, there is ongoing professional development within the Child Study Centre as staff engage in discussions with topics ranging from a specific difficulty being encountered with an individual child to policies regarding integration or educational programming at the Centre.

Formal professional development meetings are also held within the Centre where staff with different backgrounds may all contribute and benefit from each other's particular expertise. Furthermore, all staff are encouraged to attend and participate in meetings organised by the Education Department or by independent associations that address issues relevant to the education of preschool children.

UNIVERSITY TEACHING AND RESEARCH

All undergraduate students studying developmental psychology in the Department of Psychology work with children in the mainstream kindergartens of the Child Study Centre, but not all work with children in the Exceptional Children's Unit. While it is considered important to teach all students about the course of normal development, it is recognised that not all students wish to specialise further in work with handicapped children while at the undergraduate level of their training. Some do, of course, and if they show an interest, they receive encouragement. Thus over the years, undergraduate students at third year, fourth year, and Honours level in Psychology have regularly learned about learning difficulties in the Unit — for example, through completing a placement for a course requirement, through completing a voluntary placement when they can be accommodated, or through completing an Honours research project involving both normal and handicapped children. Postgraduate research projects which involve children in the Unit are also encouraged.

A further way in which the Unit is involved in learning about learning difficulties arises from the research studies of academic and research staff in the Department of Psychology. While such research will not be described here in any detail, it can be noted that over the years, studies have been conducted on the communicative abilities of handicapped children; on teacher-child communication in the Unit; on the visual processing abilities of handicapped children; on the process of normalisation of handicapped children; on the permanency of initial educational placements of children from the Unit; and on the early identification of learning problems resulting from sequencing difficulties. Some of this research relates to handicapped children in general, and some specifically to children in the Unit.

CONCLUSIONS

The Exceptional Children's Unit as part of the Child Study Centre clearly serves several interrelated functions. The extent to which it fulfils each of these functions is difficult to evaluate precisely. Whereas it is possible to evaluate some of the specific goals of the Unit, others prove more difficult. For example, it is possible to evaluate a specific program with one child if a detailed behavioural goal is set and then the behaviour monitored. A child who shows too much physical aggression may be placed on a schedule that aims to reduce aggressive acts. Such acts can be defined and a count can be made of their frequency of occurrence. The success of the schedule can then be measured by the change in frequency of the behaviour, in this case by the amount it reduces. Clearly this is an important aspect of evaluation. Such evaluation does not, however, give any indication of the success of the overall program, say, in determining appropriate placements for children once they leave the Unit. Evaluation of this longer term goal is by no means straightforward. One possibility would be to evaluate this in terms of the number of children who move to integrated settings. But, although integration is a desirable outcome, the philosophy of the Unit has been to consider the range of educational provisions a child may go to and to select the most appropriate for the child at that time, rather than always aiming for a mainstream setting.

Follow-up visits are made once the children leave the Unit, and this provides information on the appropriateness of the initial placement. This information is of value both with respect to monitoring each child's progress and with respect to future placements. Furthermore, a study is currently being conducted to evaluate the progress of children in the longer term. In this study the educational progress of children who have attended the Unit during the last ten years is being assessed and, once completed, it will provide more information about these children and the contribution the Unit may have made to their education.

In addition to the functions of the Unit that focus on the children, there are many other facets involved that also require careful evaluation. These include the involvement of the staff in the Unit, the work conducted with the parents of children in the Unit, the training of inservice teachers, and the greater acceptance of children with handicaps by their peers. Although it would be misleading to suggest that the Unit has succeeded in fully evaluating all facets, the awareness of the importance of each one, in both the short and long terms, and the steps that have been taken — for example in collecting feedback from parents and inservice teachers — ensure that the Unit fulfils its functions. Consequently, as the work of the Unit continues, so will the evaluation of its functions, in order to develop a deeper understanding of the issues involved in the education of children with learning difficulties. For just as the community recognises the importance of attempting to integrate handicapped children into the mainstream educational process, so the Exceptional Children's Unit at the University of Western Australia recognises the importance of attempting to integrate the study of learning difficulties into a wider context of learning.

It is not only handicapped children who have to learn, and be helped to learn, how to overcome or reduce their learning difficulties. There is also much learning to be done by parents, teachers, other professionals, students, and academics. Due to the foresight of its founding Director, and that of State Government Departments and the University, the Exceptional Children's Unit is fortunate to be able to provide such a wide context of learning, to the benefit of all involved.

REFERENCES

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Chapter 19

THE CHILD AND PARENT SUPPORT PROJECT: COMMUNITY INITIATIVE IN A RURAL LOCATION

Alan Hayes

Provision of services in smaller provincial cities and rural districts presents problems which are often difficult to overcome (Helge, 1984a). As a result, limited services may be available to the disabled and their families. In the United States, for example, prior to the implementation of PL 94-142 many children with disabilities either were not identified or had to make do with existing regular educational services (Helge, 1984b). The implementation of the reforms mandated by PL 94-142 has resulted in significant increases in the numbers of children receiving special educational and developmental services (Helge, 1984a). Despite the increases in the numbers of clients served, rural services for the disabled still confront many problems:

> 'These included difficulties recruiting and retaining qualified staff, resistance to change, the need for staff development, long distances between schools and services, cultural differences, geographic barriers, transportation and funding inadequacies, problems providing support services, and problems with interpreting PL 94-142 regulations in rural areas' (Helge, 1984a, p.297).

All in all, the provision of services to children in rural communities in the United States still leaves much to be desired.

The situation in rural Australia seems similarly problematic. A recent report of a study of handicapped children in rural areas of Western Australia began:

> 'The motivation for this project was a concern expressed at personal, community and professional levels, that services for disabled and handicapped children in rural areas are not adequate' (Barrie & Tomlinson, 1985, p.1).

The study highlights the twin tyrannies of distance and sparsity of population in producing the problems confronting service delivery, particularly to children with low incidence handicapping conditions.

The findings of a survey of the families of disabled children living in isolated areas of Australia (Uniting Church National Mission Frontier Services, 1985) provide the first detailed national statistics on the prevalence of disability, the needs of children and families and the availability of services. The 1220 children whose parents responded to the survey, were estimated to be one quarter of the actual number of children with disabilities in the 36 regions surveyed. If so, approximately 5250 children with major special needs currently live in isolation. The most common disabilities reported included central nervous system disorders, mental retardation and developmental delay, and ear conditions. Approximately two-fifths of the children had multiple disabilities. For 61 percent the disability had been identified prior to the age of 5 years (usually by a doctor), although diagnosis typically was later for children in the more isolated areas and for those with conditions such as mental retardation and developmental delay. In terms of the educational and developmental implications of disability, three-fifths had serious learning problems, typically in multiple areas of the curriculum and more than half of the sample had communication problems. A similar proportion showed behaviour problems, with almost two in every five children manifesting severe aggression, self destructive behaviour or other serious behavioural disturbances. Medically, one third of the children had chronic illnesses and about three-fifths had undergone at least one operation. Access to medical services frequently involved travelling long distances and the availability of physiotherapy and occupational therapy services was reported to be limited. Fourteen percent of families reported that no services were available in their region and 39 percent of families in the most isolated regions were without services.

The majority of children lived at home, and in about half the instances, the only service provider was the doctor or the local teacher. Not surprisingly, half the families indicated they were either struggling to cope or their circumstances could be described as 'desperate'. Improved services to meet their children's communication, educational, therapy and medical needs and family support services, including advisory services and respite care, were the highest ranked needs.

It appears that, as in the United States, in Australia often the only alternatives available to the families of children either are placement in an urban facility, entailing separation from family or peers, or more usually provision of rudimentary services by regular school staff (Hayes & Livingstone, 1986). The success or failure of the latter alternative seems to be associated with many factors including the type and degree of severity of the disability and the extent to which the child experiences problems of behaviour or adjustment (Hayes & Livingstone, 1986). Factors within rural communities also have been associated with the continued limited availability of services. In particular, the rural ethos, incorporating values of self-sufficiency and of 'caring for one's own', often seems to have militated against moves to improve services (Helge, 1984b).

But what of the situation for young handicapped children? In the Annual Report for 1984, the Commonwealth Schools Commission concluded:

> 'Handicapped children living in isolated areas are frequently identified by those involved in special education of young handicapped children as being amongst those most in need of assistance through early intervention programs' (Commonwealth Schools Commission, 1984, p.41).

The data from Western Australia provided by Barrie and Tomlinson (1985) and the Uniting Church survey substantiate the conclusion of the Schools Commission, and suggest that the picture of limited provision of early intervention in smaller provincial cities and rural districts provided by the national survey of early intervention programs in 1981 still prevails (Watts et al, 1981). At the time of their survey (1979-1980), Watts et al. identified only five programs in 150 towns with populations of less than 10 000 residents, and only 15 programs in cities and towns of 10 000 to 30 000 residents.

This chapter describes a program which evolved in the Queensland provincial city of Gympie. The Child and Parent Support (CAPS) project was developed to meet the needs of families with young disabled children living in Gympie and its surrounding rural district. The chapter briefly sketches the historical background to the project and provides equally brief overviews of the implementation and achievements of the project. The main emphasis of the chapter is on the examination of some of the problems encountered in developing a community-based early intervention and family support program in a rural district. The chapter ends with a description of a model for delivery of parent support in rural areas.

THE ESTABLISHMENT OF THE CAPS PROJECT

The project arose out of a common awareness, both by parents and professionals, of the limited services available, in Gympie, to young children with special therapeutic, educational, developmental or social needs. Gympie, a provincial city situated two and a half hours by road from Brisbane, serves as the light industrial centre for an extensive rural community. Faced with depressed rural economic circumstances over a number of years, an increasing proportion of residents experience problems of social disadvantage.

Historically, the Gympie district, with a total population of approximately 22 000, lacked resident specialist services for young handicapped children and received many services only on a visiting basis. Special educational and guidance support services could not cater for the needs of young children with disabilities, especially for those under the preschool admission age of 4 years. While, in principle, up to 25% of places in regular preschools are reserved for children with special needs, support for such children by guidance officers was limited because of the demands of delivering services to children in primary and secondary schools. The district did not have a preschool special advisory teacher. Other services, such as those offered by speech therapists, occupational therapists and physiotherapists, though available, either were overtaxed or not able to meet the specialised needs of young handicapped children. The lack of services, locally, often forced parents to travel to Brisbane to obtain the services their children require. In addition to the lack of specialised therapeutic and educational services, support services for the families of children with special developmental needs, were limited.

Previous attempts to stimulate government agencies to provide early intervention and family support services had not succeeded and in the place of lobbying, concerned members of tge community decided to initiate a more direct approach to the problems. In November, 1983 a committee with representation both from parent and professional groups framed an application for funding under the Commonwealth Government's Community Employment Program (CEP), to establish a community-based support service for families of children with special needs resident in Gympie and the Widgee Shire. The CEP, which commenced in August 1983, had as its purpose the improvement of long term employment prospects, particularly for disadvantaged persons who have experienced protracted unemployment. The function of the scheme was to provide opportunities for work experience and employment in community projects of social and/or economic benefit.

The Uniting Church Child Care Association acted as sponsor for the application to the CEP, agreed to provide space for the project in the building used by the Family Day Care Scheme and provided 30 percent of the funding required for the first year. The remaining funds were sought from the CEP and in February, 1984 a sum of $123 006 was allocated to the CAPS project.*

Implementing the Project

From the time of approval of the CEP grant it took over a month to refine the aims and objectives of the project, establish a Management Committee, advertise for staff, interview applicants, appoint the successful applicants and conduct induction programs. The project created positions for three project workers (in the areas of language, centre-based educational intervention and behavioural management), an administrative assistant, as well as a research assistant and cleaner. A second month then elapsed in which staff made contact with the personnel of other agencies, both locally and in Brisbane, purchased equipment, and formulated programs. In May, the project workers began compiling lists of prospective clients and accepted referrals of new clients. The clientele was to include children with special needs, aged between birth and 12 years, although priority was to be given to children 6 years and younger. As the name of the project suggests, support was to be given both to the children (including their non-handicapped siblings) and their parents.

It had been estimated that approximately 200 children under 6 years of age potentially could require the services of the project. Not all these would require direct services, rather support might be more appropriately provided to their parents and regular preschool teachers to assist them in catering more affectively for the children's developmental needs.

One of the features of the CAPS project was the establishment of case teams, with a Case Manager responsible for establishing the team and ascertaining the needs of each family. The composition of each team varied according to the requirements of each case.

Delivery of services commenced at the end of May, 1984. Four major types of services were offered: Home Visits (to establish contact, assess needs and provide support and advice), Home Programs (to be implemented by the parents with the consultative support of tge project workers), Preschool Programs (to enable implementation of a special program in the regular preschool, involving the collaboration of the CAPS project worker and the preschool teacher) and Centre Programs (which included individual and group programs as well as playgroups both for children with special needs and their siblings). Examples of centre-based program activities are appended. In addition to these services, the project workers sought and provided technical information for parents and professionals, conducted Systemic Training in Effective Parenting (STEP) programs and arranged seminars to prepare Uniting Church Family Day Caregivers to work with infants and young children with special needs. The total frequency with which each type of service was provide is shown in Table 1.

In total, 37 children and their families received services from CAPS between May and November, 1984. Table 2 summarises the distribution of the ages of the children at the time of initial contact with the project.

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* Staff of the Fred and Eleanor Schonell Educational Research Centre were commissioned to monitor the project throughout its first year. Much of the information in this chapter is adapted from the final project report: Bramley, J., Hayes, A. & Elkins, J. (1985) *Monitoring the child and parent support project. Gympie.* St. Lucia: FESERC.

Table 1.

Frequency of Delivery of Services by Staff of the CAPS Project (May to November, 1984)

Type of Service	Total Frequency of Delivery
Home Visit	79
Home Program	112
Preschool Program	73
Centre Programs	188
Other (including information provision, STEP programs and services for Family Day Caregivers)	31

Table 2.

Age of Children Receiving Services from the CAPS Project

Age	n
Birth — 11 months	1
1 year — 1 year 11 months	3
2 years — 2 years 11 months	5
3 years — 3 years 11 months	6
4 years — 4 years 11 months	9
5 years — 5 years 11 months	6
6 years — 6 years 11 months	6
7 years — 7 years 11 months	1

Of the 37 children, only 6 presented with a single area of developmental concern (3 with 'behavioural' problems and 3 with 'learning' problems), the remainder presenting with multiple problems. Language and behavioural problems were the most common primary areas of need (for 16 and 14 children, respectively), followed by intellectual handicap and developmental delay (7 children). Many of the children also had associated medical and sensory problems including respiratory disorders, visual impairment, congenital heart defects, organic brain damage, epilepsy and gastrointestinal conditions. Five children had confirmed chromosomal or genetic anomalies (including one child with Retts' syndrome).

THE ACHIEVEMENTS OF THE PROJECT

The evolution of CAPS is noteworthy in that the project represented the culmination of a coordinated effort by a diverse set of members of the community in Gympie. It provides a notable example of the way in which the collaboration of parents and the professional staff of a range of agencies can culminate in a viable project to meet the needs of families with children with disabilities and other special developmental needs. The aims of the project are listed in Table 3.

The Management Committee and project workers successfully achieved all of the aims of the project, with the exception of the establishment of a toy library (Bramley, Hayes and Elkins, 1985). The programs and support provided for the children enrolled with CAPS were viewed most positively by their parents. In delivering programs, CAPS staff liaised with the

Table 3.

The Aims of the CAPS Project

1. To establish and coordinate an individual assessment program for each child.
2. To provide an appropriate enrichment program for each child and to provide support for each family, as required.
3. To establish a toy library and parent resource library for families involved with the Child and Parent Support project.
4. To encourage full involvement of all members of the family and examine the needs of each family.
5. To maximise parent relief available in the community.
6. To be a flexible service meeting varied needs and a wide geographic area.
7. To provide a specialised service for children with disabilities and special needs, where possible utilising existing facilities and services.
8. To create inter-agency links.
9. To engender community awareness and involvement.

staff of other agencies, achieved many examples of successful coordination of services, and forged new links between agencies. Contact also was made with several families who had not been involved with the service delivery system previously, in some cases as a result of isolation within Gympie's outlying rural communities. In large measure the success of the project can be attributed to the professional talents and personal qualities of the project workers and administrative officer in combination with the energy and dedication of the CAPS committee. Both elements would seem essential ingredients in the success of a project such as CAPS.

From the outset, the merit of the project was recognised publicly by the Federal Government in providing funds for CAPS under the Community Employment Program. The value of CAPS also was recognised by the local community, and in particular by the Uniting Church Child Care Association and the Uniting Church Gympie Parish. The original planners of CAPS presented their vision of the project in a clear and compelling manner, and gained financial support in a difficult economic climate. From the initial base of Federal Government and Uniting Church assistance, the project successfully extended its support to include local service clubs, the local media, government agencies and private individuals. In turn, the CAPS project provided employment and training opportunities for six persons (the project workers, research and clerical staff) who might otherwise have been unemployed and ensured that their skills were used appropriately.

The links that have been established with the Uniting Church Family Day Care scheme represent valuable additions to the knowledge of handicap in the Gympie community. The involvement of local service clubs (e.g. Apex) in raising money for an organisation based in Gympie, also fostered community awareness of the disabled, as have the educational programs and courses contributed to by CAPS committee members and staff. It was generally felt that the CAPS project had drawn the attention of the community to the existence of handicapped people in the Gympie area.

Finally, the presence of the project drew attention to the pressing need for early intervention services in Gympie, and CAPS acted as a spur to the attempts of local personnel of the Queensland Department of Education to encourage the Department to provide early intervention programs in Gympie. The decision to establish a Special Education Developmental Centre (a special preschool) was influenced by the needs of young handicapped children highlighted by the CAPS project. By making government agencies aware of the extent of need in Gympie, the project became a catalyst for increased government activity in Gympie and district. The presence of professionals, in turn, led to increased access to specialist medical services as a result of more effective systems of identification and referral. There still is no paediatrician resident in Gympie, the nearest specialist being in Nambour. Similarly, access to specialist child psychiatric and psychological services remains an area of largely unmet need.

AN ANALYSIS OF THE PROBLEMS ENCOUNTERED IN THE FIRST YEAR OF THE PROJECT

1. Management of the project

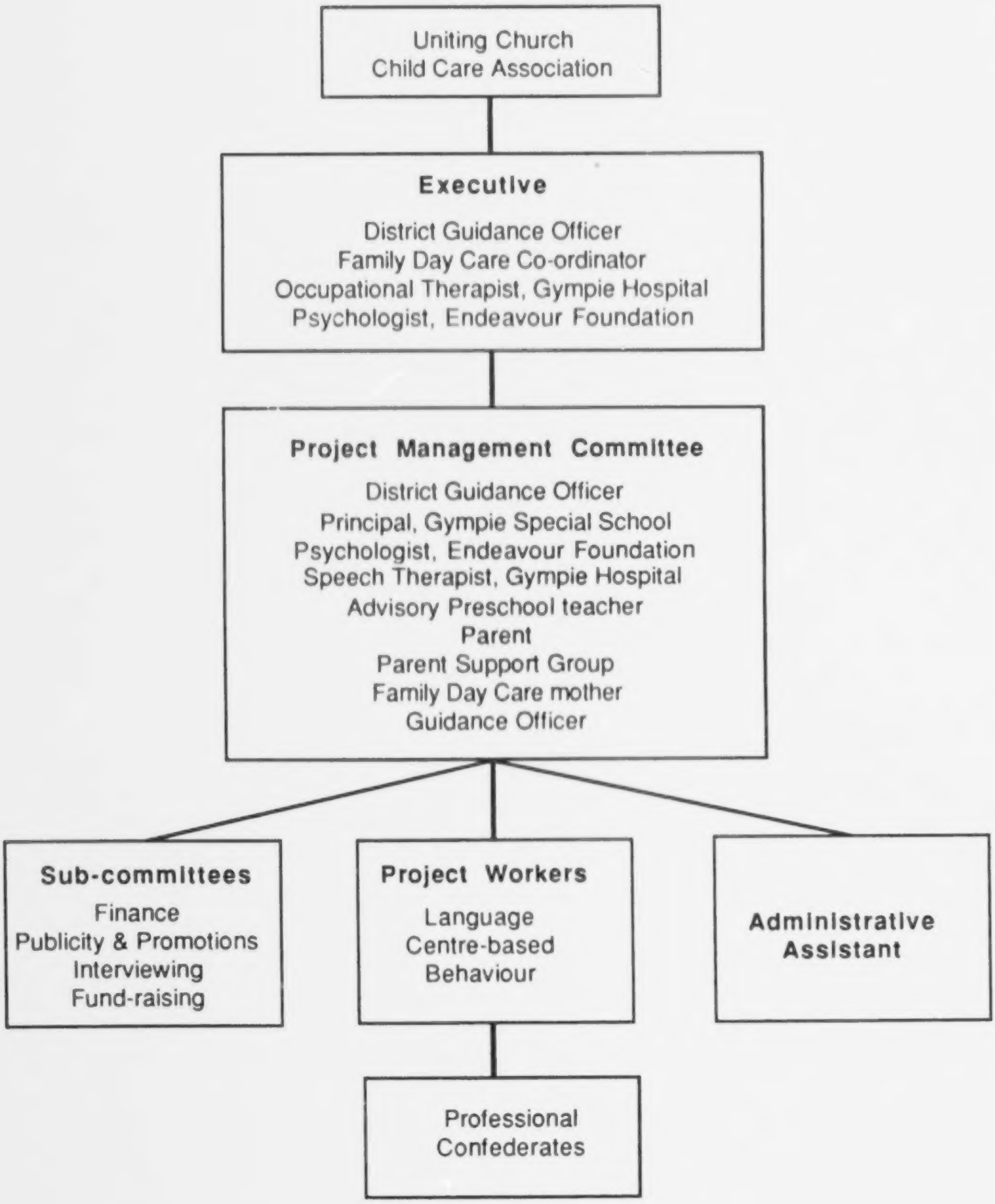
In this section it is proposed to examine the major problems perceived by the monitoring team, the personnel and the Management Committee of CAPS. For those planning similar projects, there is much to be learned from some of the problems encountered by the CAPS project in its first year of operation. It is to the credit of those involved with the project that they could turn some of these problems into points of growth for the project. For example, the need for administrative restructuring which emerged early in the project, can be seen as both a weakness and a strength of the project. With the wisdom of hindsight, the CAPS Management Committee could have benefited from a more manageable committee structure, coupled with a more realistic assessment of achievable goals. More effective management may have reduced many of the stresses and tensions placed upon those involved.

The level of stress on all involved has been a feature of the CAPS project that was not perhaps anticipated in the early days when needs were being assessed and submissions drawn up. Certainly committee members and staff emphasised that the need to succeed, coupled with the restricted time scale placed on the project by funding constraints, led to the creation of tensions and pressures which proved difficult to dissipate. From initial notions of a small-scale family support project, the scope of CAPS quickly expanded. The lack of a model of a similar project to follow, and little expertise in the running of committees, setting up systems and establishing procedures for the implementation of the project inevitably meant that committee members experienced a good deal of stress. In the initial organisation of CAPS it may have been better to have sought advice from others with experience in setting up community support projects and from professional human service and management consultants. Following the management restructuring, with the assistance of a state government management consultancy team, the project evolved a much more effective set of management structures and procedures, but only after considerable difficulties had been encountered. Figures 1 and 2 present the management structures of the project before and after the management restructuring.

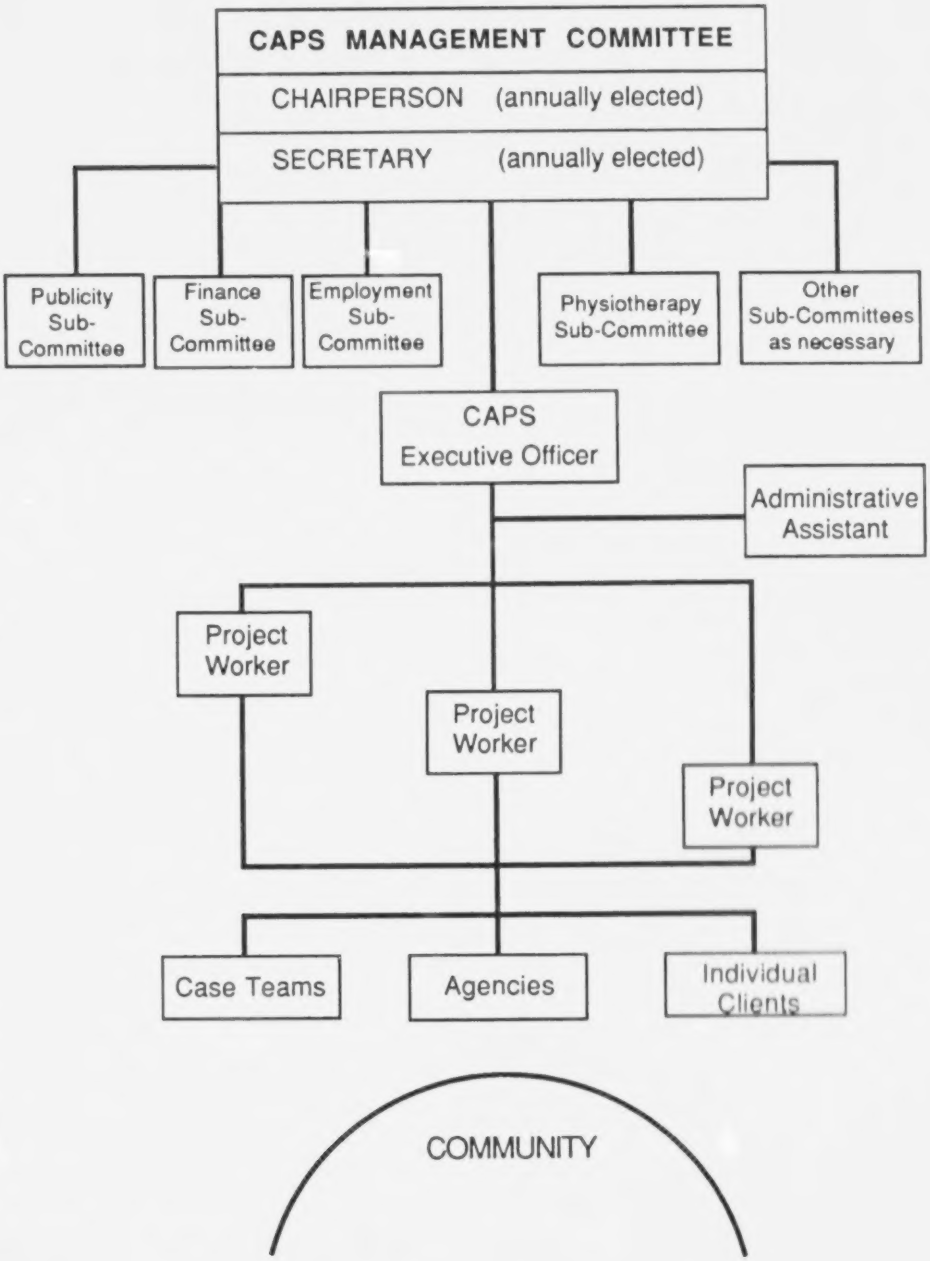
Similarly, the decision to restrict some of the objectives of the project resulted in a more effective set of programs. In particular, limitation of the toy and resource libraries, while disappointing to many members of the Management Committee, was a sound

Figure 1

Initial Management Structure for the Child and Parent Support Project


Uniting Church
Child Care Association
Executive
District Guidance Officer
Family Day Care Co-ordinator
Occupational Therapist, Gympie Hospital
Psychologist, Endeavour Foundation
Project Management Committee
District Guidance Officer
Principal, Gympie Special School
Psychologist, Endeavour Foundation
Speech Therapist, Gympie Hospital
Advisory Preschool teacher
Parent
Parent Support Group
Family Day Care mother
Guidance Officer
Sub-committees
Finance
Publicity & Promotions
Interviewing
Fund-raising
Project Workers
Language
Centre-based
Behaviour
Administrative
Assistant
Professional
Confederates

Revised Management Structure


CAPS MANAGEMENT COMMITTEE
CHAIRPERSON (annually elected)
SECRETARY (annually elected)
Publicity Sub-Committee
Finance Sub-Committee
Employment Sub-Committee
Physiotherapy Sub-Committee
Other Sub-Committees as necessary
CAPS Executive Officer
Administrative Assistant
Project Worker
Project Worker
Project Worker
Case Teams
Agencies
Individual Clients
COMMUNITY

decision. It is a better strategy for a new project to achieve a smaller set of goals successfully than to attempt an unrealistically extensive set of goals with only limited chances of success.

It is not surprising that the Management Committee experienced difficulties. Lack of experience initiating a project like CAPS was exacerbated by the pressures of limited time. This resulted not only from the pressure to get programs started but also from the fact that all committee members had full-time commitments already, and had not fully realised how time-consuming involvement with CAPS would prove to be. To the pressures of time were added the tensions which emerged as the dream suddenly became reality. There had always been a variety of interests represented on the committee. On the one hand there were representatives of church interests, on the other representatives of agency interests. Added to these two groups were the representatives of parental interests. In fact, the committee subsumed all these interests in order to establish CAPS, but once the project was underway each faction began to push more strongly for the model of service delivery that was felt appropriate. The differences in perspective emerged more clearly as the project neared implementation.

2. Staffing the project

Another problem arose over the hiring of personnel. The Community Employment Program guidelines for funding of the project stipulated that long-term unemployed persons located through the Commonwealth Employment Service network had to be employed on the project. These requirements reduced the potential pool of applicants, particularly in the project worker categories. Despite efforts made by the Gympie Commonwealth Employment Service and the Community Employment Program Secretariat, the statewide Commonwealth Employment Service network had difficulty in locating suitably qualified professionals. Through other avenues members of the CAPS committee were able to locate suitable applicants, who were still eligible under the Community Employment Program guidelines. These applicants eventually were interviewed and employed.

Because project staff did not all commence work with CAPS at the same time, the induction process was particularly difficult. Three problems involving staff occurred in the initial phase of the project. First, the Management Committee, having worked for so long to set up the project, had evolved high expectations of what they expected CAPS to achieve, and subsequently placed heavy pressures on new staff to get programs underway as soon as possible. An added factor was that project staff had not been involved in the formation of CAPS, which made it difficult for them to determine accurately their roles in the project.

A second problem also was the result of the pressures of time. The committee set about hiring staff before they had thoroughly established job descriptions and clear expectations of the roles they expected various staff to play. In addition, the arrangements for sharing equipment and space with the Uniting Church Family Day Care Scheme had not been finalised and staff, having been hired for their specialist professional expertise, found that their initial task was to make many of the logistical arrangements for the project. In a sense it appeared to project workers that, having employed them, the committee expected them to know exactly what to do. As the project got under way, the roles of the project workers evolved, and they developed team guidelines. However, they were expected to undertake many tasks and duties outside the parameters of their original job expectations.

A third difficulty concerning project staff involved the dual role played by members of the Management Committee. On the one hand they managed CAPS and were the 'employers', on the other hand they were parents of CAPS clients or professionals with other service delivery agencies in Gympie.

Many of the above problems were the result of a combination of inexperience on the part of both Management Committee and project staff, and time constraints. The employment of an Executive Coordinator for the project would have overcome many of the pressures both on the staff and on the Management Committee.

3. Funding and communication problems

By general consensus the management structure and the staffing difficulties were the two main problems experienced during the first year of the project. Other problems did exist, such as the uncertainties in the funding of the project, publicity, initial space and availability of equipment, and problems experienced by representatives of local agencies in their involvement with the project.

The lack of funds to purchase essential centre and office equipment was seen by staff as restrictive and frustrating, and uncertainties about future funding meant that people often did without things rather than spend funds which they felt may be needed later in the year. Several people indicated that they considered CAPS was publicised too early, and that it would have been better to have become properly established before advertising the project. An additional factor in publicising CAPS was the failure of the Management Committee to utilise existing expertise within the Uniting Church organisation. Problems also arose in gaining access to information. A member of the Executive Committee pointed out that CAPS staff had to seek out information that in established organisations would be readily at hand in a store of knowledge transmitted by people who had worked in the organisation over the year.

Occasionally problems occurred concerning the involvement of local agency representatives in the project. While, in general, local agency staff perceived CAPS as beneficial, several difficulties were experienced in setting aside time for CAPS work without impinging on their own agency duties. The commitments made by agency repesentatives to CAPS involved them in numerous committee or sub-committee meetings, as well as Case Team membership and inevitable meetings or telephones calls concerning CAPS clients. All this proved stressful for many people. Communication difficulties concerning the transfer of information on mutual clients also proved problematical for some agency representatives because of the differing regulations concerning confidentiality and parental access to information. In addition, some agency representatives had experienced difficulties keeping up with the volume of information required by CAPS staff, or remarked that methods of exchanging information often had been inefficient.

Many of the problems or difficulties discussed above arose through the constraints imposed by the funding of the project, the newness of the concept, and lack of experience in establishing a new organisation. Attention has been drawn to the pitfalls of establishing such a project for the benefit of others who may wish to use the CAPS project as a model.

FUTURE DIRECTIONS

Three factors seem to have converged to produce the particular pattern of services evident in the CAPS project throughout 1984. The first factor was the presence of a clientele, including many young children with a marked degree of disability, for whom very few specialised services had been available in Gympie. The second factor was the representation on the Management Committee of parental and professional groups with considerable interests in gaining access to early intervention services. Finally, and directly related to the first two factors, was the selection of project workers whose job descriptions emphasised centre-based program delivery.

In short, there was considerable pressure upon the Management Committee and the project workers to develop programs to meet the needs of the existing, 'known', clients and to fill a major gap in service delivery for young children with identified disabilities. Given the circumstances obtaining at the time, this was a most appropriate course of action. It provided a significant, tangible, and successful contribution for CAPS to make to the community in Gympie, and met the expectations of many of those who had been instrumental in launching CAPS.

The cost of such action was a lessening of the impact of CAPS in developing a network of support throughout the community. As it stands, the impact of CAPS was constrained by the scope of on-going funding and without a considerable increase in funds the project could not cater for an increased number of children. The delivery of centre-based programs, home programs and programs in preschools was at the cost of outreach, and family support largely was restricted to those families receiving direct services from CAPS programs. Given an initial estimate of the client groups for CAPS as approximately 200 children, CAPS programs have been delivered to about 20 percent of those expected to require the service. In the present mode of service delivery, it is difficult to see how CAPS staff could offer an adequate service to a wider clientele.

With the introduction of early intervention services by the Queensland Department of Education in 1985, it was opportune for the CAPS Management Committee to reconsider the nature of the service to be developed by CAPS. The presence of a special preschool teacher from the beginning of 1985 provided a service to meet the educational and developmental needs of those children with developmental problems of a moderate to profound degree of severity. Again, the extent of the service was limited, however, given the presence of a single teacher.

The first year of the project highlighted a number of major problems confronted in providing direct delivery for services via intensive, ongoing centre-based intervention programs. Invariably, the extent of service delivery is constrained by the limited capacity of staff to delivery programs to more than a small group of children at any time. Even with the availability of volunteers and/or paid aides, the project workers were still limited in their scope for developing and monitoring individual programs for each child. Further, the efficacy of intensive early intervention programs depends in large measure on the ability of an agency to offer further services which provide continuity of programming beyond early childhood. Increasingly, such programs will be provided by the Queensland Department of Education. With a major agency, such as the Queensland Department of Education, assuming responsibility for provision of a wide range of educational and developmental services for young children with disabilities, it hardly seemed appropriate for a project such as CAPS to attempt to provide complementary services.

Freed of the time and labour intensive demands of centre-based early intervention services, the CAPS project could re-focus upon other areas of support requiring less intensive modes of service delivery and therefore enabling a more extensive impact of the project upon the community in Gympie. CAPS involvement then could be extended in areas of service such as the provision of family day care and relief care for families with children with special needs.

In this model, the functions of the CAPS project would be:

1. to facilitate the development of a network of community support for the families of children with special needs;
2. to provide specialist consultative services for other agencies involved with CAPS clients, such as the Special Education Developmental Centre or the Family Day Care scheme;
3. to act as a liaison between families and the service delivery system in Gympie.

The project would act as a contact point for parents, referring them on to other services where appropriate, or providing some family support as well as providing specialist consultancy to other agencies in the areas of behaviour management and social work, for example. A major function would be to 'train' persons for day care and other voluntary involvements with clients. This model would increase the extent of influence of CAPS by decreasing the day-to-day delivery of services to specific families, while providing the types of supportive, consultative and educative services other agencies find difficult to provide given limited time (primarily as a result of the demands of providing direct services).

1. The family liaison role

The CAPS project would take on a role in family liaison and support which currently is not within the brief of any other agency in Gympie. By so doing, the project could move into an area of need rather than duplicating existing services. These functions of CAPS — to act as the liaison between families and the agencies delivering services, to monitor service needs in Gympie and to facilitate the development of community networks and resources — would represent a unique area of service.

2. Relief care and the 'second family' system

The issue of relief care provisions would need careful consideration. A range of modes of service delivery can be considered. One alternative would be to work for the provision of a relief care facility, such as a family group home or relief care centre. It could be argued that this is a costly alternative, both in terms of capital outlay and continuing costs. Another alternative may lie in the development of a system of 'second families', families within the community prepared to take children into their homes for day, emergency or relief care. The advantages of the 'second family' system are that personal networks develop linking families within the community. As such, the awareness of the needs of families with children with disabilities, as well as some of the skills to meet these needs, are distributed throughout the community, not simply vested in the personnel of the relief care centre.

Further, service delivery costs are only incurred when services are actually used, whereas with a centre-based service, staff and maintenance costs accrue irrespective of the level of demand. Additionally, should the level of demand increase at a particular time, it may be difficult for a centre-based relief care facility to accommodate the demand. An extensive 'second family' scheme could hold considerable reserve potential to meet a period of increased demand, while accruing minimal continuing costs in times of low demand.

POSTSCRIPT:

Generalising the Experience of the CAPS Program to other Communities

The experiences of the CAPS project in 1984 provide a number of lessons for those planning similar ventures in other rural communities. Similar administrative and practical problems are likely to beset any fledgling project involving the collaboration of people from diverse backgrounds with different perspectives and, at times, potentially conflicting interests. The CAPS project shows that these problems need not be unsurmountable. In addition, the project provides a nice example of one of the ironies of service delivery. Before the establishment of CAPS, pleas for early intervention largely fell on deaf ears. Once established, the strength of the case for a state government early intervention program was recognised and, to the government's credit, action was taken expeditiously.

The problems in staffing the project may be equally vexatious. The difficulties in finding and retaining staff, discussed at the beginning of this chapter, were borne out in the CAPS project. The problems, both of recruiting staff and keeping them, were exacerbated by the constraints of funding under the CEP grant, and particularly highlight the problems of provision of short-term funding for the establishment of community projects such as CAPS. Since the termination of the initial funding the project committee has had protracted discussions with both state and federal agencies to seek further funds. Apart from uncovering some mild antagonism towards the CEP and the lack of consultation with the sections of the various public service agencies responsible for specific facets of funding services for young disabled children and their families, these discussions have highlighted the continued fragmentation and lack of coordination of funding and administration of services. It is fair to conclude that the combination of health, education and welfare elements in a service for young children with disabilities, with a focus on total family support, still falls between the cracks of the many state and federal agencies whose service responsibilities lie at the points of intersection, but are far from achieving a union. In times of economic stagnation, the prospect of such a union seems even more remote. To its credit, however, the committee of CAPS has demonstrated a tenacity of purpose which has resulted, at least, in partial funding for elements of the project. Perhaps such tenacity is one of the essential prerequisites for the success of rural initiatives in the provision of services for children with special developmental needs. Another element is the ability to generate innovative ways of ensuring that community resources are mobilised fully in order to achieve a lower demand for public funding. Tailoring rural projects to make efficient use of community resources, for example, by the use of volunteers (Marrs, 1984) and by the cooperative use of resources across communities (Kirmer, Lockwood, Mickler & Sweeney, 1984) may be the only way to ensure that the perennial problems of distance and sparse population are made a little less tyrannous.

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Chapter 20

AN APPROACH TO EARLY INTERVENTION IN A RURAL COMMUNITY

M.W. Batchler
A.J. Shaddock

INTRODUCTION

Country people face unique difficulties in participating in early intervention programs. Problems of distance, lack of transport, difficult terrain and weather often preclude many children and families from involvement in such programs. Others are able to participate but in less than satisfactory ways. A major problem reported by parents in the New England region of New South Wales is that they have to travel too far to make use of services (Edwards & Shaddock, 1984). The parents also noted that when they received assistance for their child, it was given for too short a time, was infrequent and follow-up was poor. Sparsely populated areas with their small population bases and isolated communities usually do not have sufficient numbers in any client group to warrant a special service, so children with developmental disabilities are often integrated into the school or preschool system, not because country people necessarily value this approach over segregation, but mainly because there is little alternative. Integration is forced upon them.

Unfortunately there is often considerable difficulty in arranging appropriate consultation to generic services offering early intervention for children with disabilities, ie. to preschools, community health centres and hospitals. Very often the specialists are based at the larger provincial centres. This means that country children in need of early intervention or other specialist educational service are disadvantaged. Some parents, faced with this possibility, sell up and move the family to a larger town or city. This solution can result in family disruption, distancing from support networks and loss of jobs. Of course it also contributes to rural decline which is at once both a cause and effect of the general problem of service delivery in rural areas.

Staff who work in resource roles in rural, special education services also experience unique difficulties. In order to do their job effectively, they must spend a great amount of time in travelling, 30% — 50% in the New England Region for some staff (Edwards & Shaddock, 1984). They can feel professionally isolated, often having to treat or teach, knowing that their expertise in particular areas, such as in working with children who are profoundly intellectually handicapped or who have significant behaviour problems, is quite limited. These difficulties are compounded when young, inexperienced staff are recruited to rural areas. Very often their social and professional links are with the metropolitan area and many tend to regard working in the country as a way of gaining the necessary experience for a city job. Staff turnover, particularly in the therapies, tends to be high. This, of course, creates problems for team leaders and administrators who are continually recruiting, rebuilding and retraining.

It was the presence of some of these difficulties in Tenterfield, a town of 2000 people in northern New South Wales, that led to the development of a different approach to early intervention. Five children were identified as being in need of such services and all were younger than five years of age. Four were moderately developmentally delayed and the other had language delays and was said to be hyperactive. In addition, one child was considered to be aphasic and also had motor coordination problems. They were ineligible for school counsellor services and the Health Department's Developmental Disabilities Team visited only four times each year.

THE IMPLEMENTATION MODEL

Providing ongoing special 'distance education' for the five isolated preschool children necessitated weekly contact with local resource people such as the children's teachers, volunteer tutors and, where possible, parents. This contact involved ongoing assessment of the children's progress, updating of individualised program plans, and the provision of specialised materials. Key components of the implementation model, therefore, were the training of local resource people and their subsequent involvement in implementing programs, the use of highly structured educational programs, the systematic use of teleconferencing, and the commissioning of an independent evaluator to gather data and make judgment about the merit of the project.

Local Resources

The local preschool and the Catholic primary school were venues for the project. Local resource people consisted of voluntary tutors, the children's teachers and parents. A significant feature of the project was the involvement of volunteers in a high status role.

Structured Educational Programs

After consultation with the Resource Support Unit (Severely and Profoundly Handicapped) of the New South Wales Education Department, it was decided to use the Frederick's Teaching Research Curriculum as the core program for the five children. The DISTAR LANGUAGE 1 program was also used with three of the children. Highly structured individualised programs were developed around this precision teaching core.

Training

A two-day intensive workshop was conducted in Tenterfield to acquaint parents, volunteers and teachers with the Teaching Research Curriculum. Members of the multi-disciplinary resource team from Armidale also participated.

The Use of Teleconferencing

The systematic use of teleconferencing to overcome some of the difficulties associated with the education of isolated children was a significant feature of the implementation of the project. Weekly teleconferences were held between the Armidale resource team and Tenterfield personnel. Each teleconference was of about fifteen minutes duration.

Evaluating the Project

Data gathering relied predominantly on qualitative methods. Information was obtained by means of interviews with members of the Armidale team and with personnel at Tenterfield, by observation of the children who participated in the project, by the perusal of documents, including records of children's progress and other material related to the project, and by analysing tape recordings of the teleconferences.

RESULTS

Children's Progress

Three months into the program, the children's progress was formally documented for the Commonwealth Schools Commission. Child A worked on a number of programs from the Bud Frederick's Teaching Research Curriculum. She made considerable progress and after seven weeks had reached criterion on four programs, ie. completing a four-piece puzzle, running three hundred yards in three minutes, removing pants unfastened and putting on pants unfastened.

She also made gains on other programs:

- stacking five blocks of graduated sizes;
- nesting four boxes;
- riding a tricycle;
- putting on a T-shirt;
- responding to identification cue;
- expressive language, looks at mouth; and,
- expressive language, imitates mouth position.

The program for Child B was also taken from the Frederick's Teaching Research Curriculum. His erratic attendance certainly affected his progress. Nevertheless, he achieved criterion on two programs:

- completing a four piece non-interlocking puzzle; and
- nesting four boxes.

Child B made progress on one other program also, viz., stacking five blocks of graduated sizes.

During the teleconferences, principles of handling hyperactive children were discussed in detail with B's parents, teachers and the volunteer. Written material was also provided.

The remaining children, C, D, and E had very similar educational needs and were all in the same class. They made very rapid progress and completed the following programs:

- The first 21 lessons of DISTAR LANGUAGE 1 (undertaken in a group situation);
- matching colours (Fredericks);
- naming colours (Fredericks);
- personal and possessive pronouns (Fredericks); and
- comparatives and superlatives (Fredericks).

After three months, the teachers of C, D and E felt that they could cope well and there was no further need for the teleconferences. These children dropped out of the program in

1984. They are still attending regular school.

The other two children, A and B, continued in the program until the grant concluded some 10 months later. Child A now attends a special class in a primary school and child B is in a regular class.

Volunteers

The volunteers made the following comments about their involvement:

- the volunteer program worked but there really ought to be two volunteers per child, (several respondents voiced this opinion);
- The best thing about the program was the self-confidence of ——— and ——— (volunteers); they could cope;
- people might become too dependent if there were just visits; they are thrown more onto their own resources;
- sometimes it takes a bit long for our programs to arrive (programs were mailed from Armidale);
- it would be good to have a professional here daily but we're doing all right!

The pre-program workshop introduced the Tenterfield staff, parents and volunteers to the Bud Frederick's Teaching Research Curriculum. The workshop also enabled the resource team, local professionals, parents and volunteers to get acquainted. Several interviewees stressed the importance of the workshop from this perspective and credited the workshop with the later success of the teleconferences. The workshop was given front page coverage by the local press and this publicity gave the participants, particularly the volunteers, considerable status.

The participants in the workshop were asked what they had learned and gave the following responses:

- from zero knowledge of Fredericks to a much greater knowledge, plus a knowledge of precision teaching;
- the workshop was a good thing which I enjoyed. Maybe it was a little rushed but this was unavoidable. I learned a lot from the Fredericks system.
- I got new skills from Fredericks.
- heaps! The Frederick's method and different teamwork approaches.
- the workshop was valuable in showing how to approach children with learning difficulties.
- the two-day workshop was interesting. Reinforcement would be useful at a later date.

Resources

The major problem was insufficient time . . . for hiring and training staff, acquiring materials and equipment and updating programs on a weekly basis. The fact that the children attended different schools meant that some time was lost in transporting the teleconference phone from place to place.

Question seven of the interview schedule asked 'Were there enough resources?' Respondents commented:

- we needed more time . . . and secretarial assistance . . . to get the programs out in time;
- it was hard to supply equipment for the people . . . was it the right gear?
- perhaps we needed a second teleconferencing set;
- yes. We were able to use what was available locally as well;

- no. Not enough time for me to update. More time for discussion with NEED centre staff is needed;
- more time needed with the Occupational Therapist.

Structured Program

The following observations made by members of the resource team summarise their experience with the Frederick's Teaching Research Curriculum:

- the program clearly shows staff how to do a task analysis;
- the program shows teachers the value of recording and precision teaching as a whole;
- it is only appropriate for children with a global developmental delay which is moderate or severe;
- the training of volunteers and teachers needs to be thorough otherwise the clipboard becomes very confusing;
- the program is not particularly useful in developing language and is somewhat mechanical and limited.

Teleconferencing

1. Interview data

Although implementers reported some difficulties with aspects of the teleconferencing, in general there was strong support for the practice of regular teleconferencing between parents, teachers and volunteers and the multidisciplinary team. Typical responses to questions about the efficiency of this communication method were:

- a good way to deal with problems as they arise; the impact is lost if left too long. Having it weekly is important;
- gives us weekly contact if there is a problem;
- great help! The teleconferences give NEED Centre staff an idea of how the programs are going;
- the conferences seemed to be a waste of . . .'s (teacher's) time; I seemed to be saying the same thing each week;
- I was only involved in one teleconference but found it helpful;
- the people from the NEED Centre were supportive . . . they had the answers;
- I felt I knew the people and I felt comfortable;
- I didn't take part but it was good not to have to travel to Armidale;
- they are essential but maybe not every week. Teleconferences should not replace visits;
- the scheduling of teleconferences was difficult . . . so many people involved;
- a relaxed, warm atmosphere was created;
- it's a feasible way of working with Tenterfield people; and,
- good on the whole; some were a bit daunted at first. There is still a need for visits.

2. Content Analysis

The recordings of the first twelve weeks' teleconferences were analysed. Some of the major findings are presented here. (Detailed results of the analysis are to be found in Shaddock, and Batchler (1986).

The results indicated that while communication was definitely 'two-way', a major role for the multidisciplinary team was to be good listeners. For about 40% of the time, the resource team merely listened to the local support group, asked for clarification, or gave support, encouragement and reinforcement. A somewhat surprising result was that the local support group sought direct assistance only 2% of the time. About 15% of the time needed to be spent on the organisation of materials, timetabling of teleconferences and other aspects of administration. Although the use of teleconferencing equipment was new to all participants, only four percent of time was lost in dealing with technical difficulties.

In general, the results of this analysis showed that, as expected, local support groups of preschool teachers, parents and volunteers, used teleconferencing to seek some direction from the resource team. However, the major use of teleconferencing by the local support group was in their using the resource team as a sounding board and in providing them with information and suggestions about their children.

CONCLUSIONS

This project successfully met some of the needs of children requiring early intervention in a rural area. The teleconferencing approach worked particularly well when the focus of intervention was on skill development in the child. The model had more difficulty in achieving objectives for families, rather than the target child. The somewhat public interview via teleconference was not conducive to counselling. It was therefore difficult to work with parents who seemed to be denying their child's delay or whose management of the child needed to change in order to affect behavioural changes in the child. In retrospect, more use could have been made of behaviour oriented 'packages' similar to the structured educational programs (Distar and Teaching Research Curriculum).

The project was relatively inexpensive. A stringent cost comparison of this project and existing alternatives was not attempted because the teleconferencing provided so much more input to the children in Tenterfield than the other approaches (Shaddock & Batchler, 1983). However, the savings in time and money over the alternatives which involved car or air travel were substantial. A major advantage of the project was that it developed expertise and confidence at the local level. A small number of teachers, parents and volunteers were now available to respond to the special educational needs of other preschoolers in their district.

Surveys of country families usually highlight the effect of distance on their access to specialist services (Brentnall & Dunlop, 1985; Edwards & Shaddock, 1984). This project alleviated some of these difficulties for parents and staff. More importantly, it significantly increased the amount of individualised instruction the children received and led to impressive gains in their development.

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Chapter 21

HOME-BASED TEACHING IN MOUNT DRUITT

Muriel Healey

The Home Base Program was one of five experimental programs in the Mount Druitt Early Childhood Project in the years 1975 to 1979. This project followed in the wake of more than a decade of Headstart in the United States of America. Like Headstart these programs were designed to counteract some of the effects of poverty on families, specifically its effects on the educational achievement of children in these families. Three of the four sessional preschools were modelled on Headstart research. The fourth sessional program was said to be Australian in origin, embodying the values and practices of the contemporary Australian Preschool. Home Base was not a sessional program. Instead it took place in the community and its core group was the family. It was based on Home Start (O'Keefe, 1973) but differed from Home Start in a number of important ways.

The American home-based program addressed poverty factors like malnutrition by the employment of para-professionals to visit homes and demonstrate appropriate health and nutrition provisions to parents. Also the visitors stressed the importance of play and communication between parents and children while offering ideas about how to enrich these interactions. Evaluation of Home Start included developmental assessment, medical checks and a test of some interest to the planners of Home Base — the Eight Block Test (Hess & Shipman, 1968). The reason for this interest was that the test purported to assess the amount of cognitive input in a mother's communication with her child in a structured play situation. This was an issue central to Home Base which was designed to enhance the role of parents as teachers of their children.

At four Mt. Druitt schools teachers were employed to visit homes and work with parents of children of preschool age. Families were recruited by the usual procedures of the NSW Education Department when preschool experiences are made available — through publicity and interviews with parents. The four Home Base teachers were recruited from schools in the western area of Sydney after volunteering to take part in the study. All of them had experience in working with young children. They began working separately at first, one being based at each of the four sessional preschools which had been built for the Project. They offered an alternative form of preschool to the same population of four-year-olds who might seek entry to sessional preschool. However, this alternative was to prove unpopular with Mt. Druitt parents who said that they valued for their children the socialising experiences of attending group activities. Consequently all four Home Base teachers were moved to Bidwill Primary School in one of the newest suburbs of this vast housing estate. Here there was no competition for the young students. Many parents enrolled with Home Base preferring it to no preschool at all, although they did not immediately welcome the notion of becoming more closely involved with their children's education. Through home visits and school-based meetings the teachers attempted to get their message across — that parents were central to each child's growth and development and to their future success at school.

ORGANISATION

Each teacher was permitted to enrol up to 15 families. The focus child (official enrolment) was of preschool age (from three years nine months) and could be expected to attend school after one year in preschool. Younger or older siblings could be included in the home activities, making for a vertical spinoff effect especially with younger children. This confirmed the well-supported view that such intervention would have been more appropriate at a younger age. However Education Department rules would not allow this. Also the Program would have deviated even more remarkably from the others in the Project had the children been so much younger.

In practice only 13 families were enrolled with each teacher following the inception of playgroups for Home Base families. This allowed more preparation time to teachers for both kinds of activities and added to the value parents put on the program. They felt that their children were getting what they needed most — regular supervised activities with their peers. Some parents also approved the opportunity to meet others and share ideas.

Each family received one home visit of an hour or more per week by appointment. They were expected to be present. After the first year, when teachers were sometimes left to play with a child while a mother got on with her ironing, parents were asked to commit themselves to active participation on enrolment. This action on the part of teachers reflected their growing confidence in having something to offer. Absence, when not indicative of crisis, usually signalled some discomfort of the mother with the visits. The Program Advisor followed up these incidents in order to reassess the needs of the family. From time to time she also assisted with playgroup activities or parent and teacher discussions. The Program Advisor acted as both principal researcher and a participant in the Project. At various times of the year she administered assessment schedules for children and parents with help from part-time research assistants from Macquarie University.

Weekly meetings were held with the four teachers, and from time to time parent workshops were run on aspects of school involvement. Like other Program Advisors in the Mt. Druitt Project, the Home Base Program Advisor was responsible for keeping the model before the host school administrator's attention, seeking support for the teachers whenever it was needed. With other research personnel she also participated in the dissemination of information throughout the community, either through visiting other agencies or chairing meetings for parents and others at any one of the five schools which supported the Project. These encounters ensured a community profile and participant status in the ecological experiment which the Mt. Druitt Project became. The program staff acted as advocates both for their particular programs and for the families of the children who were enrolled in them.

The Program Advisors were employees of Macquarie University. They were responsible for implementing the five experimental programs and for evaluating them with generous funding provided by the Bernard van Leer Foundation. However, through the Standing Committee responsible for the Mt. Druitt Project, links were made with other institutions and departments, including the NSW Education Department, source of the buildings and the teachers, the Health Department of NSW which provided collaboration in a nutrition survey in Mt. Druitt and professional support at all times, and the Smith Family, a charitable organisation in NSW. John Braithwaite of Macquarie University's School of Education was the Executive Director of the Project.

AIMS OF HOME BASE

The broad aims of the program were:

1. To increase the parents' confidence and consciousness of their role as principal educators of their own children by:
   - (a) strengthening in parents their capacity for facilitating the total development of their own children — cognitive, social, emotional and physical;
   - (b) involving parents directly in the education of their children by showing how learning is continuous and that everyday experiences can be used as learning experiences;
2. To identify, coordinate and integrate the existing community resources and services for the provision of nutritional, health, social and psychological services for families on an as-needed basis;
3. To assist parents to increase their knowledge and understanding of child growth and development;
4. To assess with parents the needs and strengths of the family and the physical environment of each home;
5. To provide, when appropriate, diagnostic services to ensure that no child progresses through the preschool years with an undetected educational or physical handicap.

THE CONTEXT

Mt. Druitt was a well established housing estate in 1975 when the Project began. Clustered around the old village of Mt. Druitt were numerous suburbs built in stages over the previous eight years or so. To the north were the newest suburbs, Bidwill among them, as yet without paving, kerbing or guttering in some areas, with few shops or community services. One reason why Home Base was accepted here was that there was little else to offer for children. Also many women felt isolated and were happy to receive visits at home.

In the process of implementing an innovative program the researcher is faced with social forces which may assist or impede its adoption. For example, the four experimental preschool programs located at Whalan, Madang Avenue, Dawson and Mt. Druitt Primary Schools had to come to terms with pre-existing social and idealogical systems. However, these were school-based in the main. The Cognitive Program, for example, based on Weikart's Ypsilanti model (described in Braithwaite, 1983) encouraged questioning on the part of children — not always with happy results for teachers. Some parents too were not excited about their children's increased disposition to argue. The Home Base Program was not confined to school environments. The teachers sought to enter the community network and to incorporate its values, but they were teachers nevertheless and they were expected to bring school values and school knowledge to each home that they visited. When they asked parents what they wished their children to learn, some parents replied, 'You are the teacher, you should know.' As for the School, there was some uneasiness about teachers wandering about the district, bereft of classroom structure and support or supervision from senior staff. Recognition of parents' teaching status was an idea rather than a reality.

Although parents have always been their children's teachers, few parents believed they had as much to offer as the school environment. Over the years families had become distanced from schools and were generally content to leave the responsibility for education with established institutions. Parents did not perceive a relationship between their behaviours as parents and their children's growth and learning. Many school teachers did not value parents as teachers although they valued the importance of a stable and well motivated home. Home Base teachers set out to reduce the gap between home and school and found some resistance from both sides. Schools which had established an authoritative position in their communities were not necessarily regarded as sympathetic with home values. On the other hand, some class teachers feared invasion by opinionated interruptive parents if the barriers were broken, with an increase in unruly behaviour by children as a consequence. However, Home Base was to receive strong support from the Education Department and from a small group of liberal thinkers in the community. Among the latter were community nurses and other health workers in Mt. Druitt.

Health workers were anxious to get support for young mothers, many of whom were single. Changes in the 'family' over a decade or two have included role changes of parents, variable status of one parent (most often the father in Mt. Druitt) and an increased mobility of the family group. Most families in Bidwill were very young, residing for the first time in their own homes and a long distance from other supports in child rearing. Health workers hoped to see a change in the quality of parent-child relationships as the result of Home Base. They felt that many mothers had no enjoyment in their children and that this deficit was a source of behaviour problems.

CURRICULUM DEVELOPMENT

Some parents seem to be better at the task of enhancing their children's development than others. Their goals are not necessarily the same as those found in educational texts. White and Watts(1974) for example showed how well-developed children were skilled at asking for help when they needed it but were independent when they were capable of doing a task. The Harvard Study under White's leadership established some objectives for parents which included this type of achievement. This study became a major reference point for Home Base teachers in establishing individual curriculum objectives for children (White & Watts, 1974):

i. Get and maintain the attention of an adult;
ii. To use adults as resources;
iii. To have linguistic competence;
iv. To sense dissonance or note discrepancies;
v. To anticipate consequences;
vi. To deal with a range of abstract representations;
vii. To take the perspective of another;
viii. To make interesting associations;
ix. To plan and carry out multi-step activities;
x. To use resources effectively;
xi. To attend to two things simultaneously, or in rapid alternation.

The four Home Base teachers identified quickly with White's goal behaviours when they searched for a model for curriculum. Some of the criteria were more attractive to parents than others. For example, parents valued polite manners and outgoingness which would be relevant to the first two items listed, and they wanted their children to speak well. They did not express any spontaneous interest in cognitive goals phrased in these developmental terms. This was hardly surprising. However, the teachers believed that they could find strategies for helping children to develop such learning-to-learn skills as those put forward by White. Any of the experiences planned for children attending preschool might be incorporated into Home Base, the more so after playgroups were established within the program. The major emphases were the following:

1. promotion of play activities and parent enjoyment of play;
2. priorisation of language/communication between parents and children;
3. encouragement of children towards autonomy in personal matters;
4. imparting community knowledge to parents;
5. making referrals to other agencies for parents.

These priorities gave the curriculum a structure which enabled the organisation of concepts around and within the areas of

(a) home
(b) school
(c) community

Also they suggested contexts in which learning could take place in the most functional way:

(a) At home children might help in cooking or washing or planning shopping lists or unpacking groceries and storing them in cupboards. Within this context spatial, temporal, numerical and social concepts emerged in the setting of real problems to be solved.

(b) When, in the second year of Home Base, playgroups were organised at Bidwill School, the enrolled families had the opportunity of coming together and learning from one another. Group play was planned to include communication games with mothers (and sometimes fathers) participating. Playgroup included a time for mothers to be absent from their children and to have conversation with other parents about common problems in childrearing. These sessions were also very informative for teachers. Later, some integration activities took place when parents visited the school with children who were to be enrolled in formal education.

(c) Teachers organised excursions with one or more families to visit places of interest to their children — libraries, swimming pool, vegetable markets and so on. Children learned about the roles of other members of the community, handled money or books and interacted with many different sorts of people.

RECORDS

Being involved in an experimental program, teachers were required to keep many records. The central record was the teacher's account of each home visit. This involved a record of ongoing assessment and suggestions for the next weekly visit. (An example of a home visit report is appended.)

This type of recording was not time consuming. It forced each teacher to prioritise information in terms of past, present and future objectives. It was formative, linking previous with planned future experiences. A collection of weekly records could also provide summative information about teacher initiatives and client responses. Other records were made periodically by teachers. Some of these, such as the Boehm Test of Basic Concepts (Boehm, 1971), were administered on behalf of the research team. It was our belief that independent researchers could be replaced by teachers when the teaching environment was the home.

Outside visitors tended to be intrusive, although they were employed when the administration of tests required expert knowledge.

Thus it was that the Home Base teachers became proficient in using several standardised tests. They used another method of evaluation schedule which was developed under the supervision of the Program Advisor. This was TOPC, designed to record each teacher's perception of the type of interaction occurring during home visits. The Teacher Observation of Parents and Children (TOPC) was developed as a substitute for a classroom observation schedule adapted for use in sessional preschools — PROSE (Braithwaite 1983). Some of the categories of PROSE were retained; others were replaced by behavioural classifications more appropriate to the home context. While PROSE was developed for objective time sampling of behaviours, TOPC was subjective because the observer was also a participant. A TOPC record represented a teacher's perception of happenings in a home visit immediately after the visit. It rated behaviours in terms of comparative frequency (low to high) during that visit once per month during each school term. Categories of behaviour were organised according to the persons interacting:

parent to child
child to parent
child to teacher
teacher to parent
teacher to child
parent to teacher

The categories described behaviours such as initiates, praises, questions, shows/tells, and affective responses were recorded also. Over the year this set of records provided provided a climatic chart for home visits with any family enrolled in Home Base.

Several other scales were devised in order to evaluate components of the program which were considered to be critical for its success. These were structured interview schedules tapping two critical areas: (a) behaviour management and (b) verbal instruction. The first of these was **Parent Perception of Roles** (PPR), the second made use of a commercial toy ELEXICON (Ravensberger) to elicit teaching behaviour and provided analysis of the mother's language during her introduction of the game to her child.

PARENTS' VIEWS OF BEHAVIOUR MANAGEMENT

Parents mentioned discipline so frequently during home visits and school meetings that it became essential to write behaviour management into individual programs. The PPR was designed to record parents' views of themselves in a disciplinary role. It was administered at the beginning and at the end of the preschool year. Two sets of questions were prepared, one recording 'What am I like', the other 'Whether it works'. These pairs of questions referred to 50 different behavioural statements contextualised in familiar situations, for example: 'I find it easy to get him to help around the house by pretending it's a game' or 'I explain to him how silly it is to show off.' The questions were put during a structured interview organised to present the statement first, then the questions 'Are you like this?' 'Very Often? Sometimes? Never?', 'Does it work?' (i.e. what you do). Comparisons were made between responses at the beginning and the end of the year. The main result of the comparison was an increased tendency for mothers to try out what were considered to be the more positive management options while still allowing themselves occasional lapses to more negative but traditionally approved actions. The PPR, owes much to Emmerich's study of parental cognitive styles

(1969) in its conceptualisation, but also to Strom's 'Parent as a Teacher' Scale (1975) for its format.

PARENTS AS TEACHERS IN A NEW SITUATION

Elexicon is a game which can be played alone once a child has learned its structural principles. An experimenting child can learn these principles by trial and error. We asked mothers to teach their child how to play 'as if this were a new toy brought home for the first time'. Mothers practised on one of the simplest matching cards before their child was brought into the observation room.

The commercial toy ELEXICON was selected for the purpose of evaluating parental styles of instruction. It had more intrinsic motivation than the 8 BLOCK TASK (Hess, 1967) and was easier to administer. It is a simple picture association task but has the added attraction of feedback for correct responses by means of a small flashing torch. This makes the instructional task more difficult. As well as eliciting choices by association of pictured objects the adult is faced with imparting mechanical/electrical information. This trap for parents is that the sheer joy of experimenting with the torch may over-ride a child's choice of pictures. For this reason mothers were advised against handing over the torch until it was quite certain that their child understood the game. The parent must communicate to her child how to obtain feedback, and this requires a secondary matching of the symbols accompanying the smaller of the two pictures in each pair and identical symbols arranged next to a row of dots which are electrically wired. If the correct choice is made between both picture pairs and identical symbols the light will flash.

It may be noteworthy that none of the mothers in Home Base or in the Bidwill Control Group allowed her child to evade the meaningful picture association task. However, of chief interest to us was the taped recording of the interaction. It was possible to analyse the mother's instructions according to categories developed by Hess but these were amplified to include semantic categories used by mothers to elicit matching by referring to part or whole of the objects pictured.

It was an interesting task and yielded case study records which were rich with information for Home Base teachers. However, these records reflected few differences between Home Base and Control dyads. Home Base mothers appeared to be more positive and to request relevant information and feedback more often than Control mothers at the end of the experimental year. They referred less often to the symbols than Control mothers did and more often to the process of 'finding out if you are right'. However individual differences were great within groups, tending to invalidate between groups comparisons. Most of the group differences were due to the verbal behaviours of several Home Base dyads. A later comparison with dyads from a middle class suburb in Sydney gave surprising results. The differences were not as expected in the relative explicitness of meaning — rather the higher socio-economic control mothers requested a much larger proportion of feedback from their children and obtained more verbal involvement from them. They were more likely to make tentative self references such as 'I wonder if . . .' than either group of Bidwill mothers. They talked more about the processes underlying correctness feedback and said little about the matching relations. Explicit information may not be a feature of communication between educated parents and children of this age. These parents may have been more confident than Bidwill mothers in their children's ability to size up the situation. They behaved as facilitators providing organisation and directing their children's attention to structural components of the task. The results seem to suggest that language/communication habits are difficult to change in adulthood and may not warrant the kind of attention given to them in Home Base. It would seem that future programs of this type should focus on skills which parents have rather than those which they have not. Such a study of mothers' instructional style could provide the baseline information necessary for this alternate approach.

PROJECT EVALUATION

Little has been said about the sessional programs which, with Home Base, were set up in Mt. Druitt in order to study the effects of preschool experiences on the achievements of disadvantaged children. During the five year period of the field study all of these were subject to evaluation procedures designed to tap the domains of learner characteristics, contextual variables, instructional procedures and learner outcomes (Cooley & Lohnes, 1976). Learner variables included family details and physiological and nutritional information. Standard measures to assess learner outcomes included the Preschool Inventory (Caldwell, 1970), Circus Maths (1974), Boehm's Test of Basic Concepts (Boehm, 1971), the Peabody Picture Vocabulary Test (Dunn, 1970), The California Preschool Social Competency Scale (Levine, Elzey & Lewis, 1971), the Murphy-Durrel (1965) and the Marie Neale (1970) Reading Tests. There were also several measures devised by Project staff to assess language development (Belme 198) and conceptual understandings in mathematics (Healey 1978, 1980). A detailed account of evaluation procedures and results is available in Braithwaite's (1983) account which places Home Base in this research context.

It was never intended that the study should be used to find the most successful program for advancing children's later school achievements but it was hoped that any early gains might be sustained by school-based follow-through programs in the various models already set up in the preschool year. A Follow Through Program could not be arranged in the case of Home Base. The best that could be offered was a sustained attempt over three years to increase the level of parent involvement at Bidwill Community School. These efforts were not restricted to Home Base parents but there were several outstanding examples of mothers from the experimental group who achieved high profiles in their school. Most notable was the resulting 'ripple effect' on other schools in Mt. Druitt and elsewhere in the Western area. Other schools issued invitations to Home Base parents to help implement a parent involvement program, usually in the form of group activities for parents in school premises.

The extent of this effect on the Project's schools was represented most vividly at a parent and teacher information exchange which was organised one evening at the Rooty Hill RSL Club. Senior Inspectors of the NSW Education Department, principals and staff of schools, parents and community workers attended together with Project staff. After several addresses, including one given by a mother from the Home Base Program about her own and her children's learning experiences, some of the issues and problems of parent involvement, were discussed by mixed groups over dinner and attempts were made to find practical solutions.

A longitudinal study is following the progress of the remaining experimental children as they move through school. It does not appear that there have been lasting effects on school achievement. The results are like the results of Headstart Programs which evidenced 'washout effects' in school. However, it may be that later findings will reveal some unexpected results similar to the studies described by Lazar (1981). The positive delayed effects of many Headstart Programs appeared as improved self-concept and school orientation. For example, the experimental children were less often found in remedial classes or dropping out from school. These effects were more evident when the preschool and follow through programs had involved parents.

Probably, changes in parents were more readily seen in Home Base than in other programs. For example, parent responses to PEPI, a structured interview tapping parent expectations and parent perceptions of their children's school related achievements (Alexander, 1978), reflected less on specific curriculum objectives than responses of parents in other programs. When Home Base parents responded to an open question about the benefits of the Program many of them mentioned the gains to themselves.

There were notable omissions in the evaluation of Home Base. No measure was used to determine the extent to which teachers linked their families to existing community networks. Neither were parents assessed on their knowledge of child development. Probably the best defence of these omissions is to quote Raven (1980:p.129) who criticised the morality of much educational research. He said that clear distinctions should be made between the value of certain kinds of action research directed to relevant issues and options for the education authorities, and other research which is purely observational of the systems already in existence. Those matters which were not options for the Education Department, for example changes in parent viewpoints, were not sought as ends in themselves. Rather, options were offered to parents with a view to increasing their range of possible solutions to parental problems.

The Mt. Druitt Project demonstrated that the Education Department is able to implement a variety of curricula in early childhood and that each of the demonstration programs was able to involve parents in the education process. The Home Base Program was a viable alternative. Not only did it arouse considerable interest amongst school personnel at the time but it has continued to be implemented in a modified way at Bidwill Community School in conjunction with a two — unit sessional preschool.

Appendix 1

HOME VISIT REPORT (copy of one example)

Fig 1.

Date: . . . .

Materials taken to be used in session . . . .
. . . . gross motor equipment . . . .

Materials left for family to use
. . . . nil . . . .

Objectives for this visit
i. ***short term***
. . . . S.carry out specific instructions coordinate leg arm movements . . . . imitate actions. Overcome wrong action.

ii. ***long term*** (reason)
. . . . Show mother how to model and reinforce
. . . . behaviour appropriate . . . .

People present during visit
. . . . Mother S sibling . . . .

Progress made
. . . . Mother sometimes gave S praise . . . .

Problems identified
. . . . S responded to threat and upset by failure
. . . . Mother embarrassed by lack of cooperation from S . . . .

Parent observation
. . . . involved with young sibling often ignores and evades questions about S. Likes to talk about own interests.

Child observation
Will not involve herself in suggested task for any length of time. Resists verbally or passively or by withdrawal. Tries to lead sibling. No spontaneous communication. Resents questioning . . . .

Plans for next visit
. . . . Talk with mother about child's resistance and way of handling this . . . .
Have activity involving Mother and child cooking . . . .
Exploit positive aspects of activity for both.

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Chapter 22

EARLY INTERVENTION FOR MIGRANT FAMILIES AN INNER CITY EXPERIENCE

Judith Croll

> *'Everyone functions according to what is familiar'*
> *Rosetta Kai Sung, 1983.*

The Early Learning Service was established with regional funding from Youth and Community Services Community Welfare Funds in August, 1983. It was envisaged that the Service would provide an educational early intervention program to families with 0 to 3-year-old developmentally delayed children living within four local government areas of Central Sydney, as well as those of the Inner West and Canterbury. The targeted area was one with a high migrant population. Service delivery to migrant families automatically raised a number of issues associated with communication. For example, how does the monolingual English-speaking teacher adequately assess the infant from a non-English-speaking background (NESB)? What steps can be taken to identify effects which reflect culturally divergent child-rearing practices and expectations rather than delay or disability? How does the teacher develop an individualised educational program in consultation with the parent when they do not share a common language? Associated with this latter issue are a range of questions relating to programming for the language development of the non-English speaking infant and making provision for the acquisition of English. What are the implications of the decisions the teacher makes for language use in association with all other aspects of programming? Linked with the issue of communication is that of NESB families not making their way into available services. What can services do to remediate this situation? How can they ensure that their potential clientele knows they exist?

A second area of concern relates to the issues of differing cultural values and associated child-rearing practices. For example, how does the teacher promote playful interactions between the parent and the infant, with parents who do not recognise the value of play? What adaptations can be made to the curriculum and associated teaching strategies to accommodate or ameliorate divergent cultural attitudes or values?

Finally, there is the issue of parental isolation. Amongst the ethnic agencies there is considerable agreement that being a migrant is for many a lonely and alienating experience whilst being a migrant with a disabled infant is infinitely more traumatic. How does one develop a service which adequately addresses the unique needs of these families? What steps can be taken to bring them into contact with similarly affected families and available support services?

In this chapter it is proposed to consider first, those factors which influenced the development of the Early Learning Service and the delivery of the program, including the need to ensure that NESB families made their way into the service, the development of a program which would accommodate the potentially different child-rearing practices of a culturally diverse clientele and some program provision for addressing the effects of parent isolation. In later sections, the program's implementation and impact will be considered. Here it is proposed to review issues and outcomes in relation to referral, assessment, curriculum, services to parents and teachers and general items of interest to service providers. In the final section the major issues and outcomes will be summarised.

FACTORS INFLUENCING THE DEVELOPMENT OF THE PROGRAM

In late 1982, when surveying health, education, welfare and ethnic agencies operating within the targeted area, it was found that many migrant families with disabled infants were not making their way into existing community-based services. In particular, there was a need for an early childhood special education program which developed strong links within the ethnic communities, adopted a service delivery model which facilitated the access of the NESB family and adapted its curriculum and teaching strategies to accommodate observed differences in child-rearing practices. The program also needed to co-operate closely with local health and welfare agencies to provide a co-ordinated service and opportunities for the families to meet together in informal settings as one means of overcoming parent isolation.

While certain elements of existing community-based services addressed some of the needs that had been identified, there was no single individual service currently operating within the area which set out to provide a comprehensive service delivery to NESB families with disabled infants. For example, the existing educational intervention program was centre-based, which automatically prevented a significant number of migrant families from utilising the service (Garrick, 1983). In addition, the program involved the families in following a strict regimen of activities and this was seen to be particularly unsuitable for many of these migrant families (Durante, 1983). Only one of the existing health department services provided a regular home-based service to families which was discontinued when the infant reached eighteen months of age. Two services provided transport to bring families of older infants and preschoolers to their centres and this seemed satisfactory for these children. None of the existing community-based services had adequately addressed the issue of parent isolation (Durante, 1983; Koutsounadis, 1983) and none of the services gave their staff sufficient flexibility to adapt their service delivery model to suit the individual needs of a wide range of clients (Croll, 1982).

It was these factors which influenced the development of the Early Learning Service.

The Characteristics of the Target Population

The areas to be serviced were in an older, more densely populated urban and industrial part of inner Sydney with good access to transport and an abundance of local shops which catered for most cultural needs, and were well endowed with the full range of health services.

In recent years there has been a huge influx of migrant families from non-English-speaking backgrounds into the areas targeted for service delivery. Table 1 shows the distribution within the district of the major ethnic groups. Greek and Italian families represent the two largest ethnic communities, each with around 21% of the total ethnic community. A further 14% were of Lebanese and 11% of Asian backgrounds, including the Vietnamese community which was rapidly increasing in certain areas of Sydney. The remaining groups included Yugoslavs 9% and a number of smaller ethnic communities such as Turkish and Spanish speaking migrants.

Each of the local government areas in the selected region has its own particular identity which often reflects the composition of the local population. For example, Marrickville is described by Horvath and Tait (1984) as being the centre of multi-cultural Sydney with a significant population of Vietnamese, Lebanese, Yugoslavs and Greeks, whilst Canterbury has been identified as the centre of the Lebanese community. It has been observed that the targeted areas initially attract most of Sydney's migrants, partly because they offer cheaper accommodation and more importantly because they are more likely to bring people into contact with their own countrymen (Horvath & Tait, 1984).

Table 1 Showing Census Statistical Subdivision by Place of Birth

1981 Census Statistical Subdivision by Place of Birth

GEOGRAPHICAL AREA	ETHNICITY						
	GREEK	ITALIAN	LEBANESE	ASIAN	YUGOSLAV	OTHER	TOTALS
Inner West	3190	11699	2538	3331	2122	6259	29139
Canterbury	7048	4250	8021	2602	1441	3548	26910
Central Sydney	11149	5341	3571	5263	5579	13962	44865
TOTALS	21387	21290	14130	11196	9142	23769	100914
PERCENTAGE	21.2	21.0	14.0	11.0	9.0	23.5	

Note: **Asian** category includes Vietnamese; **Other** category includes minority groups such as the Turkish and Spanish.

Percentages refer to ethnic groups as a percentage of the total

Anglo-Australians living within these areas were largely drawn from lower socio-economic groups and were frequently in extremely limited economic circumstances. Recently however, there has been a trend for young Anglo-Australian professionals and intellectuals to live within the Central Sydney local government area and some as a result became involved with the Early Learning Service. The potential clientele therefore tended to be NESB migrants, lower socio-economic status Anglo-Australians and a handful of clients coming from higher socio-economic status families. However the group of primary concern was in the first category.

FACTORS INFLUENCING THE DELIVERY OF THE PROGRAM

Several factors have been identified as inhibiting NESB families from entering existing services. These included lack of knowledge of existence of such services, the family's country of origin, inability to speak the dominant language and lack of car ownership. Workers at an Ethnic Child Care Development Unit in the area had observed that there appeared to be some **under utilisation of services** for developmentally delayed children by ethnic families

(Kai Sung, 1983; Isin, 1981). Two factors identified in the literature as contributing to such difficulty were lack of knowledge of the existence of such services and the family's country of origin. A review of the local literature suggested that where non-English-speaking families knew of the services available they would use them (Kai Sung, 1983; Isin, 1981). However, further investigation indicated that some ethnic groups experienced greater difficulty than did others in locating such services. For example, Garrick (1983), who conducted a comparative study of Australian and migrant families with developmentally-delayed children living within the southern and eastern suburbs of Sydney, found that Greek families appeared to be making their way into available services, while Asian, Yugoslav and Lebanese families seemed to be experiencing some difficulty. This trend was established when Garrick's distribution figures were compared with those of the various ethnic groups within the area as shown in the 1981 Census figures. Finally, the literature reviewed suggested that there were some families who knew of the existence of services for their disabled children but due to their previous experience believed that only 'the rich were . . . entitled to them' (Author unknown, 1983 p.15).

To ensure families from non-English-speaking backgrounds knew of the existence of the service it was proposed to:

a. develop and translate an information pamphlet into the language of the dominant ethnic groups
b. distribute the pamphlet widely throughout the ethnic community
c. establish strong links with members of the various ethnic community groups
d. make extensive personal contact with health, education and welfare agencies within the targeted area
e. periodically review the referral data in order to identify groups not making their way into the program or those groups who may have special needs.

Inability to speak the dominant language was seen to be directly related to some children gaining access to available services later than their English-speaking peers. For example, in the study conducted by Garrick (1983), it was established that, despite the fact that 63% of migrant families identified their infants' atypical development within the first twelve months, as did their Anglo-Australian counterparts, there was frequently an identifiable delay in these children being finally diagnosed and obtaining access to available services. It was reported that many families had experienced considerable frustration in bringing their child's atypical development to the attention of the relevant health professional, frequently the family doctor or local public hospital doctors.

As one means of assisting families to make their way more readily into the Early Learning Service it was decided to adopt an open referral system. This was intended to enable community members, parents, ethnic groups and professional agencies to have ready access to the service. Several writers had referred to the high profile teachers have amongst many NESB families (Koutsounadis, 1981; Isin, 1981; Trevaglia, 1983a) and it was thought that the adoption of this referral system was likely to facilitate entry into the program. It was also decided to make extensive use of the Health Department Interpreter Service when working with the families to ensure that they had every opportunity to communicate their concerns and to facilitate their fullest participation in program decision making. This decision reflected the experiences of several agencies providing services to NESB families reported in the Lady Gowrie Ongoing Report of Multicultural Program (1978-80).

Car ownership was cited as another factor contributing to the difficulties experienced by the NESB families in utilising available services within the area by the Ethnic Child Care Development Unit and others within the Ethnic Community. Garrick (1983) found that 40% of the migrant families interviewed by him indicated that lack of a car and difficulties associated with the transporting of disabled children had had some influence on the families' use of services. It was decided to adopt a home-based service delivery model in order to overcome any problems which may be associated with transport.

All aspects of decision-making were influenced by the experiences of other agencies working within the area with similar families. For example, the Lady Gowrie Child Centre found that gaining acceptance within the ethnic community was an extremely long term project (Ongoing Report of Multicultural Programme at the Lady Gowrie Child Centre, Sydney, 1980, 1981). Further, it was generally acknowledged that gaining credibility within the ethnic community was likely to be a pre-requisite to their making referrals to the service (Durante, 1983; Garrick, 1983). For this reason it was particularly important to develop an educational program with sufficient flexibility to be able to accommodate the different cultural values of the families referred.

THE INFLUENCE OF CHILD REARING PRACTICES ON CURRICULUM AND TEACHING STRATEGIES

A primary objective of the Early Learning Service was to develop a program suited to the needs of families from diverse cultural backgrounds. To achieve this objective it was necessary to first identify any potentially different child-rearing practices and secondly, adapt curriculum and develop associated teaching strategies which catered for these differences.

Professionals are warned against stereotyping non-English-speaking people on the basis of their nationality. Travaglia (1983b, p.1) states that 'stereotyping glosses over all important factors like education, class-structure and internal divisions in the country of origin'. In fact, it has been suggested that stereotyping is likely to create barriers between groups of people and interfere with effective communication. However, it is generally agreed that the child-rearing practices of many ethnic minority groups are frequently different from those of the new country.

> For example, Koutsounadis (1981) outlined the typical child-rearing practices of **Southern European and Mediterranean** peoples. Briefly, she stated that the father's role was typically authoritarian, the mother's permissive. The mother was responsible for the child's physical and emotional well-being (the fat, clean baby reflecting the good mother) and had a tendency to overdress and over-protect the infant. Families frequently had no strict mealtime or bedtime routines; it was not uncommon for very young children to stay up late with the family, watching TV, participating in social gatherings or visiting family friends. The child was initially encouraged to be dependent, independence being achieved later through increasing family responsibility. When disciplining their children, face slapping was not unusual. Koutsounadis (1981) also stated that many Southern European and Mediterranean families viewed their children's play as a waste of time and of no value for learning.

A similar picture of the child-rearing practices of **Latin American** families was presented in the Cultural Diversity Papers Kit (1983); though there seemed to be a greater emphasis on conforming at an earlier age than was evident amongst the Southern European and Mediterranean families. The father of the Latin American family was the head of the family but the mother had full custody over the children. It was stated 'the child learns from an early age to recognise the parents' authority' (p19) and is expected to become an obedient, respectful and responsible citizen.

When reviewing the child rearing practices of **Asian** families (Kai Sung, 1983; Tokura, 1983) it was noted that their early experience was likely to be relatively permissive, and to encourage dependency on adult help. There was an emphasis on children acquiring an attitude of care and concern for their parents and the elderly and learning to be 'modest, unselfish and polite to adults' (Tokura, 1982, p.31). It was also worth noting that these children were encouraged to be compromising and non-aggressive when interacting with others.

The common themes which emerged from this review were the value placed on the extended family, the fact that the responsibility of child care rested largely with the mother, that discipline could reflect the families' culturally different understanding of acceptable infant behaviour and that separation of infants from their mothers was likely to be rather traumatic. In all of the culturally different groups there was likely to be an element of permissiveness, the active encouragement of dependent behaviour and a marked degree of parental concern and protectiveness. It was generally accepted that these families did not value messy play, some did not understand the function of play in infant learning and others preferred their children to engage only in academically-oriented play activities. With these issues in mind the teachers moved to consider their implications for service delivery.

The literature in relation to the implications of these observed cultural variations in the child-rearing practices of NESB families with disabled infants was extremely limited. Therefore when considering service delivery, advice was sought from professionals already working within the area. Their collective experience suggested that there would be some families who viewed the disability of their child as being a 'sickness' and consequently would expend considerable time and energy seeking a cure. Associated with this may be return trips to their country of origin, visits to psychic healers and strict adherence to curative religious practices. Others they noted may adopt a 'helpless' attitude to their child's disability which would result in their having extremely low expectations of their child's potential for development. It was suggested that such families believed that, as their child could not understand, he or she could not be expected to learn and they (the parents) could do nothing to change this situation. It was noted that the most significant problems that professionals had encountered with NESB families were a preoccupation with cleanliness associated with meals and bedtime, counter-productive attitudes to play and a lack of understanding of the developmental significance of exploration (Croll 1982). Specifically:

1. **Cleanliness** It was felt that mothers overly concerned with their infants' cleanliness were constantly interfering with or interrupting their infants' attempts to attend to or interact with objects and people in their environment and this behaviour frequently inhibited any exploratory activities of the infant. In addition, the infant was likely to have restricted access to 'messy' activities and be denied an associated range of valuable tactile experiences. Finally, it was noted that this pre-occupation with cleanliness was particularly counter-productive for the development of self-help skills (eg. feeding and toileting).

   While recognising that many of these activities were likely to present problems for the families it was important to note that involvement in such experiences represented important goals for early intervention. It was proposed that teachers should ask questions, make suggestions, model, and over time set up situations which involved 'messiness' so that the parents would come to recognise that they were not harmful to the child while at the same time demonstrating their learning potential. It was also proposed to bring these parents into contact with other parents from their own country of origin who were teaching their children self-help skills so that the parents could discuss their concerns and/or fears with them. The teachers could also take the parents to visit mainstream child-care settings where the benefits of self-help skills would be more easily identified (Khawly, 1984).

2. **Over-Protectiveness** While recognising that over-protectiveness was not restricted to the migrant family with a disabled infant, most of the professionals surveyed indicated that it was more marked within these families (Croll, 1982). It was stated that undue concern for the infant's physical well-being resulted in restricted access to experiences and exploration indoors and limited opportunities for independent play and exploration outdoors. In addition, many infants had fewer opportunities to interact with peers and most families experienced extreme difficulties with separation.

   Associated with over-protective behaviour was an element of permissiveness which was observed in the parents' reluctance to set behavioural limits, often in the belief that the infant did not or could not be expected to understand. It was felt that these early experiences often resulted in their experiencing significant trauma in adjusting to the socially and emotionally demanding mainstream child care setting.

   It was appreciated that limit setting was likely to be particularly difficult to establish in view of both the 'sickness' notion and the 'helplessness' factor associated with some parents' responses to their infant's disability. It was generally accepted that, once parents had experienced successful limit setting, they would be more likely to persist and develop a more consistent pattern of behavioural expectations. As with the proposed strategies for dealing with cleanliness, modelling and providing opportunities for parents to interact with similarly affected parents were seen to be potentially suitable strategies to use. Where families experienced extreme difficulty with setting limits it was felt it might be desirable to integrate the children into mainstream child-care settings as early as practicable. Integration into mainstream early childhood settings would necessarily be highly dependent upon the infant's level of disability. However, such integration presented a unique opportunity for the infant to conform to group expectations, to have peers as role models and for the infant to acquire some of the more complex social and interactional skills these group settings demanded. At the same time the child-care setting provided an opportunity for separation to be achieved in a supportive environment.

3. **Lack of Routines** This was seen to be one of the more potentially damaging aspects of the typical family experience of many of these infants noted by professionals working in this area (Croll, 1982). Without readily identifiable routines the disabled infant would be denied the opportunity of learning to predict what happens next, which in turn would have implications for the development of a sense of security within the framework of a known and predictable environment. It was envisaged that the families in time would come to recognise the importance of a known and predictable daily pattern of activities for their infant and that they would be rewarded by an infant who was more contented and secure and one who would most likely be somewhat easier to manage. Where families were not able to supply an observable structure it was again proposed that integration into a mainstream child care setting may be a viable option.

4. **Parental attitudes to play and the provision of opportunities for exploration** This was an area of particular concern to many of the professionals approached (Croll, 1982). It was observed that many disabled infants spent long hours within the flat or home, often 'watching' TV or with few, or simply inappropriate, toys with which to play. As previously noted, they were often afforded little opportunity to

> explore their natural environment indoors or outdoors and limited opportunities to develop physical competencies in outdoor settings. In fact, some infants had almost no opportunities to learn how to play. As exploring the environment and learning how to play were important curriculum objectives, it was proposed that one means of overcoming the effects of many of these parental behaviours would be to link teaching and play interactions in with routine child caring situations such as bathtime, bedtime and feeding time, the major aim being to develop mutually pleasurable patterns of interaction between the infant and the parents. In order to achieve this goal it was proposed that the teachers assist the parents to identify suitable toys, activities and objects within the home and the local environment which could be utilised to provide valuable learning experiences and help the parents to make simple, inexpensive toys or assist them to borrow or purchase appropriate toys as required.

The overall objective of this approach was to facilitate the development of a competent infant through a program which gave the parents the knowledge and confidence to provide adequately for their infant's individual development. In order to develop an effective individualised family program, it was decided that the teachers should locate suitable objective measures to assist them with the assessment of the parent-infant interactions and the home environment. The adoption of a home-based service delivery model was particularly appropriate for those NESB families as it gave the teachers a unique opportunity to understand the strengths and limitations of each family's personal circumstances. It would give the teachers an opportunity to develop many links with the whole family, to involve other family members with the child, model techniques for interacting and managing the child's behaviour which all the family could observe. However, it was recognised that the home-based service delivery model would do little to overcome parent isolation, which was identified by a number of professionals as being a critical issue requiring consideration when developing any program for NESB families. Parent isolation was seen to be a reflection of a number of factors including difficulties associated with being a migrant in a new country (Ghabrial, 1983), not speaking the dominant language (p.15, Author Unknown, 1983) and often the loss of the traditional kinship support pattern associated with the extended family (Travaglia, 1983a). Accordingly, it was proposed to bring families together in small groups in centrally-located homes as one means of addressing this problem.

THE EARLY LEARNING SERVICE PROGRAM

From the start, the Early Learning Service set out to develop a program which adequately addressed the unique needs of NESB families. Such a program needed to apply itself to overcome the identified range of difficulties associated with communication and in particular those associated with an inability to speak the dominant language; to make contact with its potential clientele and to develop strong links within the ethnic community and associated agencies; and, most importantly, to locate, develop and/or adapt assessment and programming resources which would enhance the parents' understanding of their own infants' development and provide opportunities for them to develop appropriate parenting behaviours.

An exhaustive review of available programming resources resulted in the project selecting the Hawaii Early Learning Profile (HELP) and associated Activity Guide (Furuno, O'Reilly, Hosaka, Inatsuka, Allman & Zeisloft, 1979) as its primary programming resource. HELP was originally developed by a multi-disciplinary team on the basis of a review of available growth, developmental scales and standardised tests, with modifications made, where necessary, as a result of implemention of the program with infants from a broad range of disability groups. Its focus was on the development of the whole child, building on strengths while at the same time working to develop areas of particular need. The profile provided a comprehensive list of skills in small monthly increments from 0-36 months across six developmental areas: cognitive, language, gross and fine motor, social and self-help. In particular, it was developed for use with a population of severely-disabled infants, many of whom came from families with culturally-divergent backgrounds. HELP's associated Activity Guide listed approximately ten suitable activities or teaching strategies per skill, included definitions/criteria, glossary, numerous illustrations and skill cross references. The profile included information regarding behavioural norms and provided guidelines for the management of potentially maladaptive infant behaviours.

HELP was selected for use with the Early Learning Service clientele because its approach was designed to actively foster the development of independent infant competencies and promote mutually pleasurable parent-infant interactions. It was anticipated that this would contribute to increased levels of parental confidence and associated positive perceptions of both the infant and self. Its recognition that successful interactions can only be promoted in a warm and relaxed atmosphere and that enrichment activities should be incorporated wherever possible in the general play activities of the family suggested the authors had developed a program which was potentially non-threatening for both the infant and family.

In fact, it seemed the use of HELP would assist the teachers to develop individualised programs which would prove to be imminently suited to the needs of a culturally divergent clientele. However, the teachers were concerned that the receptive and expressive language profiles did not appear to sufficiently reflect recent developments in theory and practice in relation to language acquisition. Accordingly, it was decided to utilise aspects of the two language programs developed at Macquarie University in Sydney, Learning to Talk (Bochner, Price & Salamon, 1982), and Tell: Teaching Early Language Learning (Cairns, Pieterse, Treloar & Cross, 1982) as additional programming and assessment resources. In addition, it was proposed to review the available literature in relation to second language acquisition with a view to identifying procedures appropriate to the language stimulation of infants from NESB families.

PROGRAM IMPLEMENTATION

Referral

The service adopted an open referral system which enabled both professionals and non-professionals to inform families of its existence. An information pamphlet was developed for translation into the dominant community languages. Later a contact sheet was developed and distributed widely amongst the potential referral agencies. The teachers were given an opportunity to make initial visits to each of the ethnic agencies within the targeted area as well as those associated with health, education and welfare services. These visits were made to inform them of the service's stated aims and objectives, and to enlist their support in locating potential clientele. The primary objective of these initial procedures was to ensure that every possible step was taken to inform members of the ethnic community and other potential referral agencies of the existence of the Early Learning Service.

Assessment

It was proposed that infants be assessed initially and thereafter quarterly using both a criterion-referenced and curriculum-based assessment inventory. The family's resources and the parent-infant interactions were to be observed both formally and informally. The UPAS: Uniform Performance Assessment System (Haring, White, Edgar, Afflick & Hayden, 1981) was the criterion-referenced measure selected for use as an independent indicator of the infant's progress whilst items from HELP Hawaii Early Learning Profile (Furuno et al., 1979) were used to complete the curriculum-based assessment which resulted in the identification of potential objectives. Assessment of the home environment and parent-infant interactions were initially completed on the basis of informal observation and later on the basis of formal observation as outlined in the HOME Inventory (Caldwell, 1975). This inventory had been used widely with diverse populations and a range of socio-economic status groups with some success (Bradley, 1982).

It was proposed that both members cooperate to complete the assessment of each child referred and that the Health Department interpreters be involved where necessary.

Curriculum Development of the IEP and IFP

In keeping with the Service's first major objective, an individualised educational plan was developed for each infant which reflected its present developmental status and family's circumstances. Family members were to be the primary educators of the infant and were visited weekly or fortnightly reflecting their need for service delivery.

The developmental objectives and associated activities were largely drawn from the Hawaii Early Learning Profile (HELP) and activity guide with items being selected in consultation with the parents. Additional language goals and objectives were drawn from Learning to Talk and T.E.L.L.: Teaching Early Language Learning. In keeping with the principles identified in a review of the second language acquisition literature (Croll, 1984) families were encouraged to communicate in their home language and initial programming emphasised the development of the infant's communicative competence in that language. This advice was intended to encourage the provision of an enriched first language experience for these infants in their home language which was seen to be more important that the acquisition of a limited code of English. Communication was a critical factor in all aspects of the development of an individualised program for the infant and the family with the result that the interpreter played a pivotal role in these negotiations with the family. The program so developed was reviewed monthly.

Home Activity Books

The teachers established a system of activity books in which translated objectives and activities were listed. However, it became apparent that there were some families who were not literate in their home language and it was therefore necessary to restrict objective setting with these families so that only one or two items were targeted at any one time. As a result the teacher often found it necessary to provide an ongoing weekly service to such families.

Services to Parents

Services to parents ranged from provision to overcome parent isolation and the facilitation of entering into mainstream services to the development of information pamphlets on topics of particular interest to parents of disabled children. Implementing a program designed to relieve parent isolation was seen to be a critical component of the program to be developed. The targeted region overlapped two health regions and families living within one region were well catered for whilst those living within the other were not so fortunate. To assist these families in particular, it was originally proposed to bring them together in small group settings in centrally located homes. Two factors contributed to the impracticality of this proposal, the first being the physical environment in which many families lived (e.g. on the upper floors of residential flat buildings or behind shops), and the second being the lack of a common language. Consequently the teachers were obliged to establish informal links between families, by taking one parent to visit another living close by, or arranging a picnic which involved two or more families with a common language.

In keeping with the program's stated objective of integrating its clients into mainstream settings wherever possible, families were involved with local playgroups, long day care centres, family day care, sessional preschool and so on. Initial contact with these groups was made with the support of the Early Learning Service teacher and where necessary the interpreter. Families interested in learning English were put in contact with the home tutoring service, whilst others who preferred to attend E.S.L. classes at the local Technical College were put in touch with occasional care facilities as necessary. A series of parent-information sheets on central topics were developed for translation into the dominant community languages. Language materials with 'how to use' sheets which could be translated were also developed. In addition, the teachers set out to make a representative collection of infant games, songs, nursery rhymes, poems and stories with the assistance of members of the various ethnic communities for the use of the families concerned.

Two part-time early childhood special education trained teachers were employed by the Early Learning Service. Each worked a six-day fortnight, visiting homes on five days with one day set aside for administration, program preparation and assessment visits. Each teacher made four visits per day with each visit lasting approximately one hour. Newly referred families were visited weekly, as were those with very young infants, more retarded infants or where families were particularly dysfunctional. Otherwise, families received a fortnightly visit. As there was no early childhood support service operating within the targeted area, infants integrated into mainstream early childhood settings were usually visited twice per term and more often if requested.

PROGRAM IMPACT

When considering the suitability of the program approach and its acceptability to the families referred, a measure of their satisfaction was seen to be their ongoing involvement with the service. Without exception, once families were enrolled they maintained their involvement while they lived within the targeted area, and several families went to extraordinary lengths to have their child placed in a child-care setting which allowed them to maintain contact with the service after they had moved out of the targeted area. In this section it is proposed to consider program impact in relation to referrals, assessment curriculum, services to parents and those provided for teachers.

Referral

An analysis of the referral data supports the concept of some ethnic groups experiencing greater difficulty making their way into services than did others. In the first two years of operations, the service received 46 referrals of NESB families. When the distribution of these referrals for the ethnic families was compared to the 1981 Census figures for the targeted areas, it was clear that proportionally more Lebanese and Asian families used the service than did Greek, Italian and Yugoslav (see Table 2). This finding contradicts the expectation that Greeks and Italians would be the largest client groups. It should also be noted that the size of the 'other' group was markedly larger than anticipated. Surprisingly, it seemed that the minority ethnic groups were finding their way more readily into the Early Learning Service than were those from the larger, better established ethnic communities.

Table 2 shows the proportion of each ethnic group living within the targeted area at the time of the 1981 Census and the corresponding proportional break-up of the NESB families referred to the Early Learning Service. There are a number of possible explanations for the observed pattern of referrals. For example, many of the Lebanese families came from Muslim backgrounds where there is no prohibition upon marrying close relatives. The service had two Lebanese families where the parents were first cousins and both families had three disabled children although not all of these children were clients of the Early Learning Service. The Asian referrals were either Chinese or Vietnamese and, once settled, these two ethnic groups have proven to be skilled in locating services. The total lack of Italian referrals may reflect the limited contact the teachers had had with the Italian community. It was personal contact with members of the various ethnic communities which had been identified as the single most effective strategy for developing a dialogue with them (Ongoing Report of Multicultural Programme at the Lady Gowrie Child Centre, Sydney, 1981).

TABLE 2 Showing 1981 Census Statistical Subdivision by Place of Birth as compared to that of the Early Learning Service Referrals

GEOGRAPHICAL AREA	ETHNICITY GREEK	ITALIAN	LEBANESE	ASIAN	YUGOSLAV	OTHER	TOTALS
Inner West	3190	11699	2538	3331	2122	6259	29139
Canterbury	7048	4250	8021	2602	1441	3548	26910
Central Sydney	11149	5341	3571	5263	5579	13962	44865
TOTALS	21387	21290	14130	11196	9142	23769	100914
PERCENTAGE	21.2	21.0	14.0	11.0	9.0	23.5	

Distribution of Migrant Referrals to the Early Learning Service

AREA	GREEK	ITALIAN	LEBANESE	ASIAN	YUGOSLAV	OTHER	TOTALS
1983-4	2	—	7	3	—	8	20
1984-5	4	—	3	4	3	12	26
TOTALS	6	—	10	7	3	20	46
PERCENTAGES	13.0	—	21.7	15.2	6.5	43.5	—

Note: **Asian** category includes Vietnamese; **Other** category includes minority groups such as the Turkish and Spanish who were well represented amongst the referrals.

Percentages refer to ethnic groups as a percentage of the total

With regard to the limited number of Yugoslav referrals, it is important to note that the Early Learning Service commenced operations within the same time frame as the Yugoslav-Australian Welfare Centre received government funding to establish a home-based service to Yugoslav nationals. However, the fact that the three Yugoslav referrals received were of children aged 24-36 months and these referrals were made by Early Childhood teachers tends to support the concept of ethnic children gaining access to available services later than other children in the community.

A further investigation of the Early Learning Service referrals over the first two years appears to validate the concern of professionals that inability to speak the dominant language may be related to some children gaining access to available services later than their English-speaking peers. Of children aged 24-36 months, the non-English-speaking client referrals were considerably greater than those of Anglo-Australian families. Referrals in this age bracket were 80% more in the first twelve months and 100% more in the second (see Table 3).

TABLE 3. Pattern of Referrals to the Early Learning Service

YEAR	1983-4					1984-5				
Age Group	*A/A*		*N/E*		TOTALS	*A/A*		*N/E*		TOTALS
in months	D	O	D	O		D	O	D	O	
0 — 6	—	—	1	—	1	—	—	—	—	0
7 — 12	—	2	1	2	5	—	3	1	1	5
13 — 18	—	4	1	2	7	—	—	1	1	2
19 — 24	—	2	1	1	4	—	1	1	2	4
25 — 36	1	4	—	9	14	—	6	—	12	18
36 +	1	1	1	1	4	—	6	—	7	13
TOTALS	2	13	5	15	35	0	16	3	23	42

A/A = Anglo-Australian
N/E = Non-English Migrant
D = Down Syndrome
O = Other disability

Table 3 could also be interpreted as reflecting a reluctance on the part of referral agencies to refer such young infants to a service staffed only by teachers. Only one Down Syndrome infant was referred to the service under the age of six months.

Another explanation of the sudden increase in referrals in the 24-36 months age bracket was that the service was offering a home-based service to children in this age bracket whereas other agencies within the area changed from a home-based service delivery to a centre-based model at about 18-24 months. Several agencies indicated it was the home-based nature of the service which prompted them to refer these older children, particularly where the families did not have private means of transport and where it was not viable to transport them to the centre.

In conclusion, it seemed that the adoption of an open referral system had not resulted in the range of referrals anticipated. During the initial two-year period the service received only two referrals from community members, two from other parents, none from the ethnic agencies or associated community groups, and the remainder from the professional referral agencies, most of which were made by only one of the two larger Health Commission diagnostic and assessment centres, a significant number were referred by teachers in long day care and preschool centres, several came from the home-based toy library service and the remainder from only two of the community health centres in the region.

Assessment

The assessment procedures adopted by the teachers proved highly satisfactory. The involvement of both teachers in the initial assessment visit resulted in each of them having at least some basic understanding of the developmental status of all the children referred as well as a limited understanding of their families' circumstances.

Although sometimes frustrating, use of the Health Department interpreters to assist with assessment did provide a workable solution to the language issue and also provided the teachers with a means of immediate validation with many of the families involved. These interpreters were well trained in assessment procedures and frequently had invaluable personal knowledge of the families and their backgrounds. Their intimate knowledge of the cultural norms to which a family was likely to adhere was also a significant factor in the development of appropriate individualised programs. The teachers experienced some concern with the use of the UPAS as the independent measure of child progress. It became apparent that this instrument did not complement the Hawaii Early Learning Profile (HELP) (Furuno, 1980) as it frequently resulted in a markedly different picture of the infant's progress. The teachers felt that if the service were to continue to use this instrument it would need to be elaborated, particularly within the area of early language and social development. As this was likely to be a long-term project, beyond the time constraints of the service at that time, they tended to rely on the profile obtained using key items from HELP to monitor ongoing programs.

Over the initial two-year period of observations many of the children were assessed by local health agencies. The teachers found that those agencies using the Griffiths Mental Development Scale (1970) for their assessment developed profiles which usually complemented those the teachers obtained using key items from HELP to monitor progress. This was an extremely useful finding because the Griffith Developmental Scale provided a norm-referenced assessment which could be used with confidence to validate the progress data the teachers obtained.

Assessment of the infant's language development was completed using a number of techniques including

- the use of tape recorders to tape language samples for later translation and analysis
- requesting parents to record all language their child used in specific settings over a number of days which would also be translated and analysed
- using the interpreter to record parent-infant language interactions to obtain samples of the infant's spontaneous language for later translation and analysis.

The adoption of these techniques, whilst not ideal, is supported in the literature (Gavillan-Torres, 1984) and provides a basis on which teachers are able to make objective programming decisions. Overall, the analysis of the data obtained in this way suggested the infant's progress was quite pleasing.

It is not possible to provide a definite statement on the value of the HOME Inventory as an assessment tool as it was used for less than six months of the two-year period being reviewed. The strength of the HOME inventory was that it gathered most of its information from observation or interview probes. However, the teachers did not find it as useful as they had hoped, as it did not seek answers to a number of questions associated with the cultural differences discussed in the earlier section of this chapter. In spite of these identified gaps, the teachers continued to use this inventory because it offered an objective measure of the home environment which supplemented their informal observations whilst they sought a more appropriate instrument for use with NESB families.

Curriculum

At all times the teachers felt comfortable about the use of the Hawaii Early Learning Profile and Activity Guide as their major teaching resource and, further, the progress the infants made would suggest that families also responded positively to its approach. The fact that it broke tasks down into very small steps made it very easy for families to identify progress. The proposed activities were in keeping with most families' level of ability, while the adoption of an environmental approach, not dependent upon the availability of expensive equipment, was extremely important for families with limited financial resources. Overall it proved to be an ideal tool on which to base the development of individualised programming for those NESB families.

The decision to encourage families to utilise their home language when interacting with their infants (Croll, 1984) seemed to be supported by the observations teachers and interpreters made in relation to the quality and quantity of verbal interactions which occurred within the infant-adult dyads. There was nothing in the data collected to suggest that the language development of these infants was significantly worse than similarly disabled infants from English speaking backgrounds in our care. The emphasis on developing communicative competence was seen to be a more appropriate objective than that of teaching these infants to speak English. There is little doubt that the linguistic environment of many of these infants would have been significantly impoverished if the teachers had attempted to make the acquisition of English the program focus.

As it is not possible to provide a range of statistics to demonstrate child progress at this time, it is proposed to share with the reader two case studies with associated progress data.

Case Studies

Antonio

Antonio is a Down Syndrome child with associated physical disabilities. He is the youngest member of a Spanish family with three young children, his elder brother and sister being both at school. He lives in a detached cottage with a small garden in Marrickville. His family comprises his mother, father, siblings and aunt. His mother is intelligent and conscientious showing an intense interest and understanding of the developmental needs of all of her children. His aunt is warm and loving and has a tendency to be over solicitous and overprotective of Antonio. The family have extremely high behavioural expectations of the two older children who tend to be rather serious and reserved. Although the family are concerned with tidiness, Antonio's toys are freely available to him and appropriate to his developmental needs. Antonio's mother is the only adult family member who speaks English and consequently she is engaged for many hours each day in assisting her husband to run their small family business. When Antonio's mother is involved in this way his aunt is responsible for his care.

This child was first assessed at approximately 4.5 months and at this time he was already showing signs of delay in all areas of development. At about 6 months of age it became apparent that Antonio was experiencing some difficulty with hearing, an observation which was confirmed by an independent hearing assessment. As a result of the prescribed treatment, his hearing slowly improved over the ensuing twelve months; however his language development has always been and remains a matter of grave concern.

The manner in which all the family members have worked together to develop Antonio's skills and competencies has resulted in an environment which is rich in appropriate stimulation; over time the family have accepted the notion of limit setting for him, and they are beginning to recognise his need for opportunities to independently explore his physical environment. They still experience difficulty in structuring the environment to encourage language use but they are aware of the problem which is the first step along the way to appropriate change. Overall, this family has been responsive and co-operative and has willingly sought information on normal child development and guidance from the teacher and health professionals involved.

The family has made good use of available community resources including toys on wheels and a local play group. It is their intention that Antonio should attend a mainstream early childhood centre until he is five or six years old at which time he may have to be enrolled in a special school as there are presently no integrated OA or OF placements available for children such as Antonio (who falls mainly within the mildly delayed range of disability) within the targeted area.

On the basis of the teachers' ongoing assessments using items from HELP it seems reasonable to suggest that expressive language and self help skills are presently the areas of most marked delays. The observations were also confirmed in the assessment completed using the Griffith Developmental Scale. Antonio should make rapid improvements in the use of language and the acquisition of self help skills such as feeding, toileting and dressing when he is placed in the more demanding mainstream early childhood setting. In the meantime, it is proposed to utilise the play group setting to commence emphasising the development of these skills in the hope that the family will recognise their importance and consequently work more effectively on them at home.

Simon

Simon is the elder child of a Lebanese family living in a two bedroom flat situated on the second floor of a budget priced apartment block in Lakemba. Soon after he was referred to the Early Learning Service, his mother gave birth to her second child, a daughter. At the initial assessment visit, both parents were present and the father appeared to be deeply concerned about the well being of his son. At this visit it was established that the parents were first cousins and that Simon's father, who had recently been retrenched from his job, was unemployed. Neither parent was proficient in the use of English. Simon was attending a local playgroup at least once each week.

Over the following few months Simon made some dramatic developmental gains. In spite of these gains the teacher concerned became aware of a marked antipathy in the behaviour of his mother towards caring for her infant children. She frequently seemed despondent and disinterested. In time, the mother revealed that she felt she was directly responsible for her son's disability. Apparently, soon after his birth, she had taken her child to the outpatient's department of a local hospital and had overheard the interpreter explaining to another Lebanese parent the treatment the doctor had prescribed for her young toddler. The mother discussed her child's illness with this other parent and returned home with her baby without seeing the doctor and put her tiny baby on a water only diet for a considerable time. She became concerned when his condition did not improve and returned to the hospital. This time she saw the doctor who diagnosed the critical nature of her son's malnutrition and admitted him for immediate treatment. Whether or not the mother's behaviour had contributed to the son's disability is not the central issue, instead the teachers felt deeply concerned that this mother seemed convinced that she was responsible and apparently had a negative perception of herself as a mother. In order to deal with this situation the teacher referred the problem to the relevant health professionals.

When Simon was almost three, he was enrolled in the local child care centre. The staff in this centre had had no previous experience in catering for special needs children and Simon's behaviour deteriorated rapidly in this setting. The Early Learning Service teacher helped the staff learn to set appropriate behavioural limits and to have realistic expectations of his ability levels. Once having achieved these objectives, the situation for Simon both at home and at the child care centre began to improve. Figure 3 provides a detailed picture of the very pleasing progress Simon has made since his enrolment with the Early Learning Service.

Services to Parents

The informal links established between parents and the emphasis on linking families into mainstream services proved particularly effective in bringing parents into contact both with other families and with locally situated services which were readily accessible to them. However, the fact that so many of the NESB families from were not proficient in English created a range of problems. It effectively curtailed any concerted effort to develop parenting skills in a potentially less threatening group situation. It meant the teachers were heavily dependent upon the skills of the interpreter to convey recommendations to parents, and the teacher was not able to judge the parents' response to such recommendations. It made the use of the Home Activity Book less effective as teachers were dependent upon the interpreter for translation and it prevented them from being able directly to use these for the communication of problems and difficulties parents experienced with items in the program. Where one parent was reasonably proficient in English and the other was not, the burden of the English-speaking parent considerably increased. The growth of a range of support services associated with the Ethnic Child Care Development Unit represents a valuable source of potential support for families associated with the Early Learning Service.

The financial constraints experienced by the service resulted in there being insufficient funds available to translate the materials the teachers had developed into the dominant languages. This meant families were denied access to a rich source of information and materials for use with their infants. In view of the service's stated objective of developing a service expressly designed to meet the needs of NESB families, the lack of funding for translation is regrettable.

Service to Teachers

Teachers in early childhood settings provided an ESL program for disabled NESB toddlers in consultation with the Early Learning Service staff. Those toddlers integrated during the first twelve months of the Early Learning Service's operations had acquired a reasonable receptive understanding of English and were using a limited vocabulary within the first year of attendance at these centres. These children continued to make steady gains in the acquisition of English during the second year of operations.

SUMMARY AND CONCLUSIONS

When reviewing the data in relation to the first 24 months of service delivery, the teachers were satisfied that the adoption of a home-based model was appropriate for a project with a target population of families from non-English-speaking backgrounds. However a number of specific issues should be kept in mind when such a program is established. For example, it was essential to the success of the program that the teachers develop strong links with other services within the ethnic communities; however, such links were no guarantee of referrals from these agencies. An additional problem here was the fact that the limited nature of the available funding prevented the service from translating and printing its pamphlet in the local community languages. This undoubtedly restricted knowledge of the service within the ethnic community, so that the adoption of an open-referral system did little to encourage referrals from the whole range of potential community sources. Without translated pamphlets and coverage within the ethnic media, it was extremely difficult to make contact with families who had not already been identified and who were not already receiving services from the various health and welfare agencies operating within the area. In fact, the financial constraints placed upon the service in this regard restricted its potential to locate the group for which they had been funded to serve.

Any service catering for a culturally diverse population needs to carefully monitor referral data to ascertain whether they are reaching the whole range of ethnic communities living within the targeted area. Where they have not been successful in doing so, efforts should be made to ensure the appropriate agencies and community groups are aware of the service being offered. Further, where referrals from one community group seem excessive, steps should be taken to ascertain whether this group represents a special needs group who may require a more specialised service delivery.

The use of the Health Department interpreters proved to be a satisfactory solution to the difficulties associated with assessment and programming for infants from NESB families. They can ensure that English-speaking members or friends of the client family do not embellish or misinterpret the information being presented to the family. The employment of multi-lingual or bi-lingual staff who are themselves migrants provides a useful point of identification for many families; however, this does not necessarily overcome difficulties with communication, and indigenous mono-lingual teachers may be equally effective.

The teachers were not satisfied with the use of either the UPAS: Uniform Performance Assessment System or the HOME Inventory with their diverse population of NESB clients. However, the use of the Hawaii Early Learning Profile and associated Activity Guide proved satisfactory with the migrant families and the majority of the infants made steady progress. The decision to encourage families to interact with their infants in their home language had positive implications for all concerned. The proposed strategies for dealing with culturally divergent child-rearing practices were more successful with some families than with others and any attempt to bring about change in attitudes and associated behaviour must be viewed as long term.

The isolated-teacher model adopted by the Early Learning Service raises a number of issues requiring further consideration, including those associated with administration and streamlining of service delivery and program preparation. For example, staff associated with any service catering for NESB families must have ultimate flexibility in order to adequately cater for the needs of these families. This may involve staff in out-of-hours and weekend appointments. In addition, no project catering for NESB families should be established without additional funding being targeted for translation and printing of both promotional and programming materials.

In view of the foregoing it seems that, over the initial two years, the project has progressed towards resolving some of the difficulties associated with service delivery to NESB families. At the same time it has identified a range of issues associated with the attitudes of some referral agencies, adequate service promotion, the need for staff to have flexibility in delivering a service to their clients, the need for the provision of clerical staff to perform semi-skilled and non-skilled administrative tasks and proposed strategies for the streamlining of many aspects of service delivery. In addition, it has identified the over-riding restrictions associated with programs for NESB families having funds targeted for translation and printing purpose. It is to be hoped that these issues will be addressed when other projects of this type are being established.

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Chapter 23

EARLY INTERVENTION SERVICES TO CHILDREN IN DEPARTMENT OF EDUCATION PRESCHOOLS, N.S.W., 1983-1985.

Coral Kemp

It would be difficult to convince a professional working in this field that early intervention was not an extremely valuable service. We can all cite individual cases that have been outstanding successes despite an earlier pessimistic prognosis. Outstanding cases may not be sufficient to prove the value of early intervention to the outsider but occur frequently enough to keep those within the field dedicated to the task.

A review of preschool intervention programs by Lesley Reader (1984) discusses some of the early intervention projects that have been developed since the Project First Chance was established in the U.S.A. in 1968. Reader considers the difficulties involved in evaluating the effects of early intervention programs including the proposed beneficiary (child, family, both), the desired outcomes, the use of norm-referenced as opposed to criterion-referenced tests and the use of control groups. Despite such difficulties, long-and short-term evaluation is vital to the continuing development of quality services.

Information regarding early intervention services to disabled youngsters attending Department of Education preschools in New South Wales, needs to be discussed in the context of the preschool services offered by the Department of Education in this State and the policy regarding the enrolment of children with special needs. In the following discussion, data collected over the three years 1983-1985 are related to the services the children received prior to and during enrolment in the preschool and their subsequent educational placement.

PRESCHOOL SERVICES, N.S.W. DEPARTMENT OF EDUCATION

(a) The Preschool.

The N.S.W. Department of Education has 64 preschool centres which are housed in the grounds of primary and infants schools and which are the responsibility of the principals of those schools. The preschool teachers are considered to be members of the infants departments within the schools. Although the Department of Education has had some involvement in preschool education since the first half of this century (Ginns, 1984), the majority of the centres were established in the years 1975-1978. Most of these are in disadvantaged areas of Sydney, although there are seven centres in the Hunter, five on the South Coast, one in Tweed Heads, one in Albury and one in Narrabri. They are generally single or double units and enrol children the year before they are eligible to attend school (i.e. prior to 1987, at 3 years and 9 months and from 1987, at 4 years and six months, provided the 4th birthday falls before 1st August in that year).

The preschool centres are subject to the same regulations that apply to the rest of the school. There is, however, a separate preschool policy statement which covers matters that relate specifically to the preschools. Included in that policy is a statement on the enrolment of children with disabilities.

(b) Enrolment of Children with Disabilities.

The preschool policy provides for the inclusion of children with special needs into Department of Education preschools. Children with physical, intellectual or sensory impairment may be enrolled as long as consideration is given to:

> 'the teacher's ability and willingness to cope with particular cases;
>
> the availability of supportive services;
>
> the suitability of the building and grounds for children with disabilities.' (section 6(a))

Policy also suggests that a trial period, where the parent and child attend together for the first three or four weeks while a decision is being made on the value of the placement, may be advisable in some cases. The decisions of whether or not to enrol a child should never depend on the ability of the child to be mainstreamed into the infants department of the school as preschool enrolment does not entitle the child to infants school enrolment. Policy states that the principal of the school may give priority of enrolment in cases of special need as long as the necessary age requirements are met.

(c) Resources from within the Department of Education.

Because Department of Education preschools are not given a funding supplement for enrolling disabled children, they do not have the same facility for employing a special aide or purchasing extra resources as do other preschool centres. However, they can apply for integration funding through the School's Commission, though children are generally enrolled for the following year, after applications for integration funding have closed. Generally the child would have had to have been on the waiting list for some considerable time and the parent to have advised the preschool teacher of the disability in advance, for such an application to be feasible. Such application can be made more easily where a child spends a second year in the preschool. Unfortunately the first year is usually the most difficult as far as the teacher is concerned. Centres are not permitted to reduce the preschool numbers in order to allow more time for individual programming for a disabled child. The numbers are set at 25 per teacher in a single unit and 20 per teacher in a larger centre. The incentives to enrol disabled children are, therefore, not great. As a result, Department of Education preschools do not enrol as many disabled children as most other preschool establishments. Most would not have been identified as disabled before enrolment.

Despite the lack of special funding, the preschool centres, because they are a part of the total education system, have many sources of support if they enrol a child with special needs.

These include:

- The school counsellor,
- Specialist counsellors for the physically handicapped and language disordered,
- Itinerant teachers for the visually handicapped, hearing impaired and behaviour disordered,
- The school executive,
- Any special education expertise within the school,
- Specialist services within the community including Area Health Centres, Assessment Centres and Early Intervention Services.

In addition, because the preschool policy indicates support for the mainstreaming of disabled children at the preschool level, a preschool special education consultant position was established in 1978 to assist preschool teachers with integration programs. Teachers could request the assistance of this consultant through one of the three preschool consultants who advised on matters relating to preschool education within the N.S.W. Department of Education (1983-5). The preschool special education consultant could not offer teachers on-going individual programs for every disabled child in the preschools. It was the consultant's role, instead, to assist teachers to develop these programs themselves.

EARLY INTERVENTION PROVISION FOR DISABLED CHILDREN IN DEPARTMENT OF EDUCATION PRESCHOOLS.

(a) **Definition of the Disabled Population.**

Over the three years 1983-1985, Department of Education teachers requested the assistance of the preschool special education consultant for more than 250 children. Many of these children presented with behaviour, articulation and social problems. Occasionally a child with outstanding talent was referred. In considering early intervention services I will confine my discussion to those children who presented with a significant disability, defined as follows:

(1) Children diagnosed as developmentally disabled by school counsellors, Regional Education Department clinics or Department of Health assessment agencies;

or

(2) Children identified by their teachers as having difficulties in coping with preschool activities and who, when assessed on a developmental checklist, performed at best in the year below age level in at least two of the major developmental areas (gross motor, pre-academic, language, social). These children might be performing primarily in the 3-4 year range developmentally when chronologically they were in the 4-5 year range.

This definition excluded those children who had articulation or behaviour disorders only, though it did not exclude those who had additional learning problems. It excluded some children with specific language problems. However, some children who qualified for placement in a special language class had deficits in other areas, primarily social and fine motor. Children with a significant visual or hearing loss were not included unless they had been formally assessed as having a primary intellectual disability. Children with sensory disabilities are well catered for in terms of early intervention both within and outside the Department of Education. All children with a significant sensory disability are entitled to itinerant teacher support at the preschool level.

Of the children referred during the period 1983-1985, a total of 154 met one or both of the definitions for significant disability as described above. This number by no means represents all children with disabilities who attended Department of Education preschools during that period. I estimate that over 11,000 children attended Department of Education preschools between 1983-1985, of whom the 154 children represented approximately 1.4%. Even if the number of children requiring services for the sensory impaired or the behaviour disordered were included, this would be well below estimates of the percentage of children needing special education services at some stage during their school career.

Of course not all teachers referred children with suspected learning problems. Some teachers do not want outside assistance, either because they feel able to cope with the problem themselves or they see little value in the assistance that might be offered. Teachers from centres in very disadvantaged areas often have many children with low performance levels. A child who might be a problem and therefore readily referred from a preschool in a more favourable location might not be seen to be a problem in a centre in a disadvantaged area. On one occasion I was requested by an early intervention service to assist with a client of theirs who had enrolled in such a preschool. Their psychologist assessed this child, who had cerebral palsy, to be about a year behind his age level. His preschool teacher believed him to be one of her average to better preschoolers and so felt that special guidance was not required.

Of the 154 children who met the criteria for significant disability, the majority had mild disabilities. Not all children were assessed on norm-referenced tests. Those who were, were assessed on a range of tests including the W.I.P.P.S.I., the Stanford-Binet and the Hiskey Nebraska. Of the 81 children given norm-referenced tests, five had I.Q. scores below 30 or were 'not assessable' on the test used, 26 were assessed in the low mild to moderate range (I.Q. 30-60), 17 were assessed as having average to above average intellectual potential but with specific problems which allowed them to meet the second criterion for significant disability and the remaining children were assessed as having a mild intellectual disability (I.Q. 60-80).

Because the norm-referenced tests commonly used do not offer guidance for individual programming they were not sought as a matter of course. A further 12 children were given multidisciplinary assessments through Department of Health assessment facilities. Without the assistance of an I.Q. score, these children were assessed as having a developmental disability. I.Q. scores are still necessary when assessing for eligibility for special placements within the Department of Education. Where special schools or integrated classes were thought to be appropriate, children were referred for intellectual assessment.

Many of the children formally assessed were assessed after they had enrolled in the preschool. Some of these were already known to assessment centres and were assessed to determine intellectual status before entry into formal school. Others were given intellectual tests when they were referred for comprehensive multidisciplinary assessment. Others still were assessed by Department of Education guidance personnel after the child's ability to cope with a kindergarten placement in the following year was questioned.

The 61 children who were not assessed through Department of Health assessment facilities or by Department of Education guidance personnel met the second criterion for significant disability. Most of these children were thought to have mild disability. A small number suspected to be functioning in the low mild range of intellectual disability or below had intellectual assessment delayed because they were returning to preschool for another year in 1986.

(b) Services Provided Within The Preschool.

Most of the 154 developmentally disabled children had individual objectives set for them within the preschool program. These objectives were based, in part, on the results of developmental assessments but were influenced equally by the immediate need for the children to be accommodated in the preschool and later to benefit from the preschool curriculum. Another consideration was the projected placement for the child in the following year. If the child were to be attending a regular kindergarten class in the following year, the program objectives were likely to become more pragmatic and concentrate on the skills most likely to achieve successful integration. These would generally be social, and in particular group participation, skills rather than the kinds of pre-academic skills designed to boost progress on developmental scales.

Teachers could afford little time for direct one-to-one instruction. In preschools individual programming cannot and should not equal one-to-one instruction nor should there be withdrawal for special teaching sessions unless this is short term and part of an overall plan for integration. In this case the end goal is for the individual program to become a natural part of the general preschool program. In fact, teachers often reported that children resented one-to-one instruction and appeared to be better motivated when they participated with their peers in a learning activity. In such circumstances the disabled child would be influenced by the model of response of other children and provided that small group instruction were designed to allow a variety of levels of response, he or she would still benefit from this form of instruction.

Unfortunately, program delivery in a group situation reduces the number of times the child is able to practise each targeted skill. Because of this, the disabled child has a much greater advantage if he or she has already received an early intervention service or is currently receiving such a service. The aim of the preschool placement should be to reinforce programs that are provided outside the preschool, to generalise the skills learnt in more structured situations to spontaneous free play situations.

(c) Services Provided Outside The Preschool.

The N.S.W. Early Intervention Association's definition of early intervention emphasises the importance of planned and individualised, educational, therapeutic programs before entry into school. Of the 154 children included for discussion, only 50 children had received some form of early intervention before enrolment into preschool. Twenty-three of these had speech therapy services only while the remaining 27 had a multidisciplinary, interdisciplinary or transdisciplinary service involving a contribution from one or more of the following professions: special educator, occupational therapist, physiotherapist, speech pathologist and psychologist. The above models of service are defined by Rebecca Fewell in her discussion of the team approach to early intervention (Fewell, 1982, pp.302-3).

In the multidisciplinary approach a number of disciplines are involved in the intervention model but they generally operate separately. The interdisciplinary approach requires consultation among the various disciplines involved. The transdisciplinary requires professional involvement which crosses traditional professional roles. It was sometimes difficult to ascertain just which of these models of service the children were receiving.

Of the 46 children either formally assessed or suspected to be more seriously disabled, those for whom special O.F. placement (for moderately intellectually disabled children) was a consideration, 10 received a more comprehensive early intervention service before entering preschool. Eight such children received speech therapy services only. Seventeen more mildly disabled children received the more comprehensive early intervention services while 15 of the less disabled children received speech therapy services only. The children receiving more comprehensive early intervention services more often had diagnostic labels (e.g. Down Syndrome, Spina Bifida, Cerebral Palsy, Epilepsy, Muscular Distrophy) than did the others.

Sixteen of the 27 children receiving the more comprehensive service had diagnostic labels while only two of the 23 receiving speech therapy services only had such a label. One of those children was labelled as autistic after an assessment given half way through his preschool year. According to the results of developmental assessments conducted on children during their time in the preschool, all children in the sample who were receiving speech therapy only, before preschool, needed an individualised educational program as well as a specific language program.

Of the 27 children who had received the more comprehensive early intervention service, nine dropped out of the service some time before or at the same time as they began attending preschool. The remaining 18 continued to enjoy the benefits of both services although it was likely that the early intervention service was not as intensive as it had been earlier.

Of the 23 children who had received a speech therapy service only, prior to preschool entry, 19 continued with the service while four dropped out, on or before entry into preschool. Two out of those four were referred again during their stay in the preschool.

Most of the children who had not received services before enrolling in preschool were subsequently referred to services. In some cases parents did not wish or were unable to take advantage of these services. Even where parents were eager to receive services, referral was often a long and difficult process. Many children were referred for speech therapy services when a more comprehensive service would have been more appropriate. Early intervention teams prefer to take younger children or have strict geographical boundaries which leave many children ineligible to receive such services. Over the years 1983-1985 a further 60 of the 154 children were referred for speech therapy while a further 19 children were referred for more comprehensive intervention services. Unfortunately long speech pathology waiting lists meant that children received very little therapy, sometimes none at all, before leaving the preschool. Where early intervention teams were prepared to accept the 4- to 5-year-olds they could usually offer programs for a short period of time only as five is often the upper age limit for early intervention services.

PLACEMENT AFTER PRESCHOOL

Wherever possible, parents were encouraged to keep their developmentally disabled children in the preschool for a second year. This allowed the child more time and more opportunity to develop skills before having to cope with formal schooling. It also made possible another educational option for some children. The O.F. integrated classes for moderately intellectually handicapped children are not available to many children until they reach six years of age. A second year in the preschool made this a reasonable alternative to a special school placement or normal class placement for those children assessed in the low mild to moderate range of intellectual disability.

Some parents preferred not to accept another year of preschool for their children. Although Department of Education preschools are free, the majority of them are sessional (five mornings or five afternoons per week) and therefore do not suit those parents who believe that their children need more time in an educational setting or for those who wish to work. Of the 154 children in the sample, 34 children returned for a second year while parents of another 18 children indicated that their children would return to preschool in 1986. A further five children had part time kindergarten placements as well as their preschool placements in 1984-1985 while the parents of another four children agreed to similar arrangements for their children in 1986.

Following their stay in preschool, the majority of children enrolled into a kindergarten class at their local school. Eleven children enrolled at special schools (Departmental and private) and ten children enrolled into Department of Education integrated O.F. classes. Six children enrolled into special language classes (O.L. classes). A small number of children left the preschool without the staff knowing what school they would be attending the following year.

DISCUSSION

(a) The Quality And Availability Of Early Intervention Services: How Well Are The Mildly Developmentally Disabled Serviced?

The majority of developmentally disabled children attending Department of Education preschools are mildly disabled. Nevertheless they are children identified as having difficulties in coping with learning activities even at the preschool level. As a rule preschool teachers do not overreact to children with learning problems unless these problems are severe. They are trained to accept that children have a range of development levels and that it is the teacher's role to assist children to develop at whatever rate they are capable.

Early educators believe that the first five years are significant in a child's life, therefore children entering the unfamiliar preschool environment for the first time need an adjustment period. Children, even those with very obvious learning problems, are therefore not referred for assistance for several weeks, sometimes months. It is not unusual for a child to be referred in the latter part of term two or even in term three. By this stage the teacher would have confirmed his or her concern about the child's development. Unfortunately this often reduces the possibility of an early intervention service before school entry. It may also delay the setting of individual objectives within the preschool program. Teachers are quicker to refer children who have been diagnosed as having developmental disability.

Only about one-third of the children in the sample received an early intervention service before attending the preschool and almost half of those received speech therapy services only. Those who have a diagnostic label, regardless of disability, appear more likely to attract comprehensive services than those who do not have a label. The majority of mildly disabled children would not be labelled and may well be disadvantaged by this, especially with regard to access to early intervention services.

There appears to be a reluctance to label children at too young an age. I would not suggest that all children at risk of developmental disability have an intellectual assessment and be labelled with a degree of intellectual disability. What would be more useful would be a multidisciplinary diagnostic assessment which would identify children with possible developmental disability and precede an appropriate early intervention service. Even if the services that followed were purely preventative then they would be still valuable to the child.

Children were referred for multidisciplinary assessment from preschools when they had suspected medical or neurological problems. It was often very difficult to find a truly multidisciplinary assessment service that was located reasonably close to the child's home and which did not have the stigma of being a service for the 'retarded'. The local area health centre seemed to be the most logical choice, but these centres often lacked the range of professional staff needed or lacked staff experienced in working with young children. Unfortunately, not all assessment centres saw their role as one of seeking appropriate early intervention services for their clients.

The greatest percentage of the population of developmentally disabled are mildly disabled and they appear to receive the least number of services. The Department of Education does not provide specialised services for these children before the age of eight. It is argued that to provide the service is to label and to channel into special education services before the child has the opportunity to try out in the regular system. This effectively means that these children will usually not qualify for individual intervention during the critical years 0-8, unless they are referred to and accepted for an early intervention program before entry into school. It is not always easy to identify these children before school age. If they have a diagnostic label, a traumatic birth history or sensory impairment they are more likely to receive an early intervention service. Many will be referred to speech pathologists from preschool centres.

Even if mildly disabled children are identified before school age as needing early intervention, there seems to be hardly enough services to go around. Many of the services that are available are obviously not integrated services. A parent may be taking his or her child to a hospital or area health centre to receive two separate services from different professionals. This puts a great burden on the parents especially if they have to use public transport, travel long distances or plan the day around school starting and finishing times. Only six of the children in this sample received a home-based early intervention services.

It seems unlikely that the quality and availability of early intervention services to the mildly developmentally disabled will improve while there are so few services. In the meantime, as speech pathologists appear to see a large proportion of children receiving early intervention services, they need to refer more children, especially those who have receptive as well as expressive language problems, for developmental assessment in the hope that some of them will attract more comprehensive services.

(b) Continuity of Educational Services From Early Intervention to Formal School Placement.

The desirable progression for the developmentally disabled child must surely be from early intervention to preschool and then to school. If the child's education is to be of the highest quality then there must be communication and co-operation among these services. Unfortunately this is rarely achieved.

1. From Early Intervention to Preschool.

Although early intervention services generally sent reports of their client's progress to the preschools, visits to the centres were rare. Several factors contributed to this. Early intervention personnel are usually busy with their individual caseload. Even though a visit to a preschool might be considered valuable, it is time consuming and, unless it is given intelligent consideration by both parties, can achieve little for the child. There is sometimes a lack of appreciation by the preschool teacher and the intervention worker of what each party has to offer the disabled child. The early intervention worker who does not have early childhood training or experience may not feel comfortable in a preschool or with the aims of the preschool curriculum. It is possible that some may even doubt the value of what appears to be an unstructured educational environment. On the other hand, very few preschool teachers within the Department of Education have had training in special education. They may, as a result, feel uncomfortable with special education training strategies.

Only two of the early intervention services, used by children attending Department of Education preschools 1983-1985, had an inbuilt facility for preschool outreach, and only one of those services was able to offer regular preschool visits. Every early intervention service needs such a facility if the services to disabled children are to be better co-ordinated. The model of operation for that outreach person needs to be much more a consultant role than a peripatetic teacher role. That particular worker would need to be sympathetic both to the aims of the intensive early intervention program and the aims of preschool education and masterfully to be able to combine the two.

Sometimes the intensive nature of the early intervention program is slowly phased out once the child begins preschool. In this case there is still a role for an outreach person to link the two services before the early intervention program finally stops altogether. Unless this service is available there will be a break in continuity of the education program which may well diminish the impact of the service that has preceded and make it difficult to capitalise on the service which follows.

2. From Preschool to School.

The majority of the 154 children identified as developmentally disabled had enrolled or would eventually enrol into regular school classes. It is unlikely that relevant educational information will always follow those children to their next placement.

Preschool teachers usually keep a developmental profile on each child in the preschool. Some teachers have reported that attempts to pass on these reports to kindergarten teachers are not always greeted with enthusiasm by the receiving teachers. An opportune way of passing on information to the child's next teachers is through staffroom discussion. Although preschool teachers are members of the school staff they do not share the same morning tea or lunch break. This means that opportunities for passing on information in a relaxed and unthreatening way are lost.

Of course not all preschool children move on to the infants department in that same school. Many of the disabled children who enrol in regular kindergarten classes would not have attended a Department of Education preschool. They may have attended any one of a number of preschool establishments, or may have moved straight from early intervention programs into school. In these cases there may be even less chance that valuable information reaches the kindergarten teacher.

Even where information is passed on it may not be useful to the classroom teacher who, once again, may not have special education expertise and may need guidance to use the information within the context of his or her classroom. During the three years 1983-1985 I was able to give direct guidance to the kindergarten teachers of seven of the 154 children surveyed. This assistance was requested by the schools but it was not my role to offer such a service.

In the same way as there needs to be a link person between early intervention services and the preschool, so there needs to be a person to help ensure continuity of programs from preschool to school. If the preschool has reached a certain stage in teaching the disabled child to follow instructions and to participate within a group teaching activity, failure to take advantage of this progress could well disadvantage the child at the kindergarten level. This would be a waste of much of the effort expended at the preschool level.

The link person needs to understand what is expected of children both at the preschool and the school level and be familiar with the child's progress to date. Once again the role should be a consultant or resource teacher role and not that of peripatetic teacher.

CONCLUSION

Early intervention services which include an educational component have operated in this country for over a decade. Despite considerable support in the literature for services of this kind, early intervention services in N.S.W. are still unco-ordinated, poorly funded and poorly staffed. The result is that finding an early intervention service for a four-year-old is a 'hit or miss' affair. The child is often too old, not sufficiently disabled or lives in the wrong suburb. While researchers still argue over the critical components of early intervention, none would dispute the child's right to appropriate services from the point of diagnosis. Until sufficient appropriate services are available the children included for discussion here will never be adequately catered for.

The continuity of education from early intervention into school is critical to the long term success of early intervention programs. At each of the stages, early intervention, preschool and school, teachers achieve some outstanding successes with disabled children. Often these successes are isolated because continuity in achievement does not appear to be highly valued. Of course, in retrospect, educators can question the value of the early intervention that children received. Between early intervention and school many opportunities have been lost and there has been some failure to capitalise on skill development. If skills are not used, do not become building blocks for new skills or are not generalised into self maintaining environment situations then they may well be lost. Early intervention is dependent for its success not just on good programs and quality staff but also on being a valued part of a continuing education program for the disabled child.

POSTSCRIPT

The Preschool Special Education Consultant position was abolished towards the end of 1986. In 1984 the Department of Education seconded a number of teachers to train as early childhood special education teachers. Four of these teachers were employed in a pilot program in two schools in Metropolitan West Region in 1985. The program was extended to other regions in 1986 and the number of early childhood, special education positions continues to grow. The role of these teachers is still being clarified and the relationship between them and the Department of Education preschools is still uncertain.

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Chapter 24

NOAH'S ARK TOY LIBRARY

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The growth of the toy library movement in Australia should be seen in the context of an increasing understanding, within the field of early childhood education and, more recently, early intervention, of the place of play in the social, cognitive and language development of children.

This chapter describes the development and operation of the Noah's Ark Toy Library in Victoria. Initially, play and the relationship of toys to play are considered. The characteristics of a toy library are then outlined and the emergence of the toy library movement, throughout the world, is described, followed by a brief history of the Noah's Ark Toy Library. The function of the library is then reviewed, with details of its varied services and mode of operation.

Play: a cornerstone of the toy library philosophy

Overall, play provides a means for children to explore their environments freely, following those things that interest them, without fear of failure. Play can be solitary, but it most frequently involves small groups, often comprising peers but also younger or older children and adults. Recent research has highlighted the critical role of interaction with others during play for learning to occur(eg. see Bruner, 1983; Bullowa, 1979; Field, 1980; Kaye, 1982; Piaget, 1953; Uzgiris, 1979; Vygotsky, 1976) and one important function of toys is that they can provide opportunities for such interaction through cooperative play and, as a result, function as an important vehicle for learning. It is this aspect of toys that underlies the importance of the toy library movement for children with special needs and, in particular, for the implementation of programs in early intervention that are often based upon activities involving games with toys played by children and their caregivers.

Adults tend to separate play from the rest of their lives and to consider that it belongs with leisure and recreation, distinct from the serious business of work. But play is an integral part of a child's life not an optional extra. It is not something that children go outside to do, nor decide to do when they have spare time. Play is the way they spend their time, how they learn, how they discover and explore both the world and their own emerging skills. Through play, the developing child is able to gain experiences that contribute to growth, learning and expression. Facilitating play behaviour and promoting ideas, materials and equipment through which play can be developed is a basic cornerstone of toy library philosophy.

Understanding the importance of play in the development of children with special needs is also a critical component of the toy library's operation, which incorporates the use of toys and associated play behaviours for therapeutic purposes. Here it is recognised that many of the richest experiences of young children, particularly those with special needs, come from contact with the people who interact most often with them, including parents and other family members (who can become playthings for the child), but most importantly, the primary caregiver, usually the mother, who has responsibility for the child's care during much of the day. However, children with disabilities or developmental delays are frequently less involved in social interaction and play than their non-disabled peers and, when they do play, their behaviour is often at a lower developmental level than that of their peers (eg. Berger & Cunningham, 1986; Casby & Ruder, 1983; Terrell, Schartz, Prelock & Messick, 1984; Whittaker, 1980). Noah's Ark's approach, therefore, encourages mothers and caregivers to interact spontaneously with their children in play situations. Through the background and experience of staff, together with appropriate planning of programs and selection of materials, the library aims to systematically help children with special needs to learn to play. Parents and caregivers are helped to see the children's cues and interpret their behaviour, in order to build on the earliest and smallest indications of emerging play skills. Emphasis is placed on the need to ensure that 'real play' is preserved, with the role of the adult seen as one of inviting the child to engage in an activity, rather than imposing an activity upon the child.

In planning a program for a particular child, the behaviour of the child is observed and discussed with the parents. Developmental steps and stages are reviewed with reference to the child's present level of functioning and the next step that could be encouraged. For example, the ability of a baby to focus and look at an object could be considered when the infant is at the stage of beginning to look at objects; parents might be encouraged to teach the baby to follow a slowly-moving object visually. Suggestions are made to consolidate these emerging skills and appropriate toys and activities are identified.

Toys and the disabled child

A toy library is not a 'Christmas Tree' available for loan. It is a source of the 'tools' that are a vital component of children's play (Bruner, Jolly & Sylva, 1976). Toys are not the only means by which children play, but they are an important component of much activity that can be described as play.

It can be argued that disabled children often need toys more than children who are developing normally because their development often proceeds more slowly than their peers', so that they spend a longer time at each developmental stage. If they are not to become discouraged, bored or frustrated, they will often need a greater variety of toys at each phase in their development. Children who are severely disabled, particularly those who are physically limited, may need toys that have been specially designed to encourage the development of their skills. They may need toys to encourage and stimulate them to explore and learn about the nature of the world, as other children are able to do on their own, without special help. Some severely disabled children are slow to respond to people and events around them and this can be discouraging for parents, particularly mothers who usually have responsibility for the daily care of the child. Through its toys and trained staff, a toy library can help mothers learn how to play effectively with their disabled children and through such activity, begin to communicate and have fun.

> Toys . . . can be used to draw a handicapped child outward and forward, to help her interact with the world she lives in, both things and people; to enrich her limited experience so that, where the ordinary child learns by a sheer multiplicity of opportunities, she may

> learn through an intensified learning situation; and, by giving her a taste of exciting possibilities, to help her to push forward her own boundaries. (Newson & Head, 1979, p.145)

What is a toy library?

A toy library can be many things. At its simplest, it can be a place which lends out toys rather than books. It may be run by volunteers, parents, professional staff or a combination of these. It can be housed in a library, community centre, health centre or a house. It may be associated with play groups or other units that provide services for young children. However, the first toy libraries were established for disabled and disadvantaged children and their families. Those set up for disabled children, such as the Noah's Ark Toy Library, generally use the toys as a focus for the provision of other services (eg. physio or occupational therapy). They also provide an opportunity for families to break through the isolation that is often experienced when there is a disabled child, and support is given to the family as well as practical assistance in caring for the child. But whatever the kind of services that are offered, wherever it is housed and whoever runs it, the toy library is based on an acknowledgement of the importance of toys and play for children.

The Toy Library Movement

There are now toy libraries throughout the world. The first toy library for disabled children was established in Sweden in 1963 on the initiative of Karen Strensland Junker, Associate Professor of Paediatrics, and Evy Bild, teacher, both of whom were psychologists and mothers of disabled children. The toy library movement grew enormously in the succeeding years and that growth is indicative of changing attitudes to the disabled and an appreciation of the value of play in the development of disabled children (Newson & Newson, 1979). There have been three International Conferences (in 1979, 1981 and 1984), attended by representatives from more than 30 countries. At the 1984 Conference in Belgium, an international steering committee was formed to bring toy libraries throughout the world towards an International Association. In Australia, Noah's Ark Toy Library has been a catalyst in forming both the Victorian and the Australian Associations of Toy Libraries and was instrumental in the establishment of the International Library Association which was formed in May, 1987. Its formation was confirmed by twenty countries and the Secretariat has been established in Turin, Italy.

Establishment of Noah's Ark in Victoria

Noah's Ark Toy Library began operating in the Caulfield Community Centre and was at first open once a week and on the first Sunday of the month, run and staffed by volunteers. The distinctive aspects of those promising beginnings were the keen interest shown by a wide range of professionals and other interested citizens in a project that was not a government initiative, and the fact that the library was non-aligned. Because the Noah's Ark Toy Library was not initiated by government nor even, in its first years, government funded, it has been able to define its own structure and determine its own growth according to the perceived needs of Library members. It has continued to be non-aligned (i.e. not part of a government bureau or any medical, evaluative or clinical services) and has been able to maintain its non-threatening and independent characteristics. The result of this has been that any negative experiences which families may have had with other agencies or services are not carried over in their approach to the Noah's Ark Toy Library. It is worth noting, in addition, that because of the value of its beginnings and its unique mode of operation, Noah's Ark Toy Library has been very cost efficient for the governments which have funded it.

In 1973, the Toy Library moved to premises in Prahan which were made available, rent free, by Prahan College of Advanced Education. The following year, it was decided to open the Library five days a week. As a result, the Library was able to approach the Department of Social Security for funding support. Partial funding by both the Department and the Health Commission began late in 1975, but the Library is still partly funded by membership fees and donations. In 1975, the present Library building, a suburban house in Windsor, was rented; it was purchased in 1977 by the State Government and the title is held by the Incorporated Body of Noah's Ark Toy Library. The Management Committee, which is elected annually by users and contributors, consists of twelve people who represent a balance between therapists, parents and other interested citizens. Since the Library became an incorporated body under the Health Commission in 1982, four members of the Committee retire each year, but the remaining members provide strong continuity.

The Noah's Ark Toy Library

i) Aims

Currently, the aims and objectives of Noah's Ark are to:

1. Provide for parents a centre of guidance with professional help and advice on choosing and using toys and equipment.
2. Provide a supply of therapeutic, creative and sense-stimulating toys to help disabled children overcome their physical, mental, emotional and perceptual disabilities.
3. Help disabled persons and their families overcome the isolation and over-protection to which they are subjected.
4. Provide locations where disabled persons and others can meet, play and develop social confidence, imagination and speech.
5. Provide a program of recreational activities for disabled persons.
6. Provide a service for the distribution of toys and equipment anywhere in the geographic area served, to disabled persons who, due to their handicap or distance, are unable to attend the Toy Library.
7. Integrate the Toy Library into the overall network of community services for the disabled.

The keynote of Noah's Ark Toy Library is flexibility and this has been maximised by the structure, staffing and organisation of the Library which have enabled it to respond to perceived needs with a minimum of delay and expense, and to adapt services as required. It should be noted that there is a very small staff turnover and the benefits of that stability for children and their families cannot be overestimated. In fact, the Library has grown larger and more quickly than might have been predicted and this growth may be accounted for by a number of factors, such as:

- the need, previously unrecognised, for such a facility
- the shift, during the last decade, from institutionalised care for disabled children to home-based care (and the consequent need for greater support for families)
- recognition of the possibilities for development of disabled children
- increased concern to integrate disabled children into the community
- increasing awareness of normalisation principles

- expansion of research in the area of children's play and parent-child interaction
- economic restraint in the late 1960's and beyond that has led to a need for cost efficient delivery systems.

ii) Function

While Noah's Ark has an early intervention focus, the service continues to cater to the needs of families with disabled children from birth through to 20 years (see Figure 1). Many of the services flow through from the 0 — 6 age groups to teenagers; the Library may be described as an innovative and flexible support service for children with special needs and their families. This focus is evident in the following principles, upon which the Library has developed its service function:

1. The family as a whole is the focus of the service, with the changing needs of each member being considered in relation to the needs of the child.
2. Parents have the right to be involved in the choice of services they need for themselves and their child and to have influence on the way these services operate.
3. The relationship between the professional worker and parent is one of resource person/facilitator and acknowledged competent caregiver.
4. The child's particular needs are seen as many-sided.
5. A transdisciplinary approach is followed; i.e., a type of interdisciplinary function which involves not only mutual sharing of assessment results but also professional involvement across traditional boundaries (Bochner et al., 1985).
6. The Library functions as a developmental service with therapists providing a bridge for parents as decision-makers.
7. The Library services remain flexible in order to respond quickly and effectively to changing needs, as expressed by parents, staff and the community, as well as those brought to our attention by researchers and co-workers in the community.

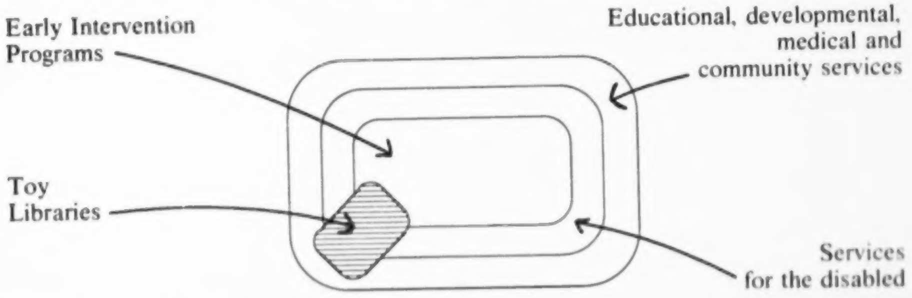
The parents are respected as the continuing and primary caregivers for their children and are supported in this role by the staff, who, in addition to being experienced therapists, have extensive counselling skills. When parents visit the Toy Library, whether for half an hour or a day, someone is always available to make a cup of tea and talk with them. This opportunity for discussion allows time for airing problems, sharing achievements of the child, discussing latest visits to the doctor, asking advice on a range of issues (eg. feeding, toileting) and borrowing toys, with staff and parents together observing the child and deciding the appropriate material. It was from this approach that a wide range of family-centred services have developed.

iii) Relationships with other services

Noah's Ark functions as part of a network of services within the community for children with special needs. This relationship with other services, including early intervention programs, is demonstrated in Figure 1 (Elkins et al, 1980).

Close links are maintained in a variety of ways with hospitals, colleges, clinics, schools, preschools, infant welfare services, paediatricians and other professional workers. Library services are used extensively by a wide range of agencies, and this interchange has proved to be extremely important, in fostering exchange of information and informal evaluation. Projects have been developed in cooperation with other agencies; for example, the sibling project in conjunction with Melbourne University; playgroups in conjunction with the Spastic Society;

Figure 1.
Relationship of toy libraries to other community services


Early Intervention Programs
Educational, developmental, medical and community services
Toy Libraries
Services for the disabled

and development of remote control switches in conjunction with the Spastic Society and Swinburne Institute of Technology. In addition, the Library helps and encourages families to look beyond its services, by providing parents with referrals, information and practical advice about other resources available in their community.

iv) Operation

From the start, it was obvious that Noah's Ark Toy Library would do more than lend toys to disabled children. Early in the history of the Library, therapists became conscious of the emotional needs, not only of the children, but also their parents and siblings. At that time, there was little consideration of the families of disabled children. As has been noted already, Noah's Ark occupies a unique position among support services, in that it is not aligned to any evaluative medical unit, nor to any educational agency and situated, as it is, in an ordinary house in a suburban street, it provides a uniquely non-threatening environment for parents and siblings. The staff reinforce that environment in a number of ways. For example, they do not require that appointments be made. There is no doorbell (a note attached says it is not working and invites callers to come straight in) which means that no one is kept waiting on the doorstep. Moreover, parents are not expected to have reached any recognition of the nature and extent of their child's handicap. Staff are all highly experienced and have good listening and support skills. In addition, they are aware of the differences in cultural background of many non-English speaking groups in the community, and of their varying reactions to both disability and support services. It has always been the practice at the Library to deal with each family's needs individually and to be aware of the unique nature of each family.

Usually it is the mother who has the care of a disabled child. Most mothers speak of the 'isolation' they experience with small children, and that isolation is magnified enormously when the child is disabled. One mother explained that mothers of disabled children are isolated because they have given birth to the child everyone dreads, and isolated again because they continue to love the child (National Women's Advisory Council, 1980). Those feelings of complete isolation — from other mothers, perhaps from their own husband, and from their own hopes — can make it extraordinarily difficult for a mother to break out and seek support. The apparent informality of Noah's Ark Toy Library makes it easier, since mothers can simply telephone directly or just call in. At the Library, they will find that they are welcome as people, rather than being seen primarily as the mothers of disabled children, and they will meet other mothers and children, as well as trained staff.

Noah's Ark Toy Library is close to public transport and there is plenty of off-street parking, but it is not possible for all those who want to use the Library's facilities to get there. So mobile services were begun in 1974, in response to the needs of those in the outer metropolitan area of Melbourne and in country areas. There are now two vans which visit 31 areas on a regular, monthly basis. Calls are made at private homes or at community centres, and the same two therapists are in attendance at each visit. The services offered from the vans are the same as those offered at the central Noah's Ark: toys for loan, counselling and guidance. In the past a truck also used to visit country centres on a bi-monthly basis. These visits, which involved local professionals and volunteers, covered most parts of Victoria. However, six regional Noah's Arks have been established and since these have developed their own outreach programs, the truck has been discontinued. Since 1984, a car has been used for home visits. The car carries no logo or identification to ensure that the privacy of those at home is respected.

The six regional Noah's Arks (at Geelong, Wangaratta, Bendigo, Latrobe Valley, Swan Hill and Ballarat) grew out of the van visits from Melbourne. Each has the same philosophy as the central Library, and meets the needs of the region; each has its own Management Committee. Funding and overall administration come from the Central Noah's Ark and funding is dependent on the regional toy libraries maintaining standards. The Regional Noah's Arks keep contact with Melbourne in a variety of ways, including two-way visits and in-service training once a term in Melbourne.

Playgroups: Noah's Ark has been running early intervention playgroups since 1973, following the playgroup movement philosophy of including parents and siblings, as well as the disabled child. However, before entering a playgroup, families take part in either individual or group sessions with the physio or occupational therapist. During these sessions, the parents' goals for the child, in relation to playgroups, are discussed and these goals become the basis for that child's program in the group. Structured, individual programs follow a developmental model and are directed towards the needs of each child. Progress is evaluated after each session. All programs are implemented by members of a transdisciplinary team who are trained to be sensitive to families' needs. An awareness of the processes of adjustment and an understanding of how to listen and respond to help personal growth are skills developed by staff through discussion, on-going study and in-service courses. Parents are supported during all stages of therapy and there are many opportunities for them to be in contact with each other for mutual support, sharing of information and friendship.

Playgroups at the Library developed in response to needs expressed by parents. These needs take many forms, such as a desire to meet other mothers, the absence in the home neighbourhood of playmates for the child, sibling rivalry, ignorance about what the child should be doing and when, lack of ideas to keep the child occupied, worries about delays in speech, mobility and general responsiveness, as well as feelings of loneliness, despair and fear.

Play is the work of children, we are told. For all our members, the opportunity to play is important, just because they are children. Sometimes it is difficult for young, disabled children to obtain places in normal playgroups in their home district for various reasons, such as severity of handicap, insufficiency of such groups locally or an inability of the child to tolerate large numbers of children. There is then a risk of the child, already disabled by a disability, being further disabled by deprivation of an experience important to normal development. The playgroups at the Library are, therefore, valuable in that they provide a normal experience for our younger members. They also, of course, help to meet some of the other needs expressed above, such as the opportunity for mothers to meet and the provision of ideas about play at home. Our playgroups are, therefore, in a sense, informal physio, occupational and speech therapy sessions, but they could also be equally well called early intervention, sensory-motor development or speech stimulation groups. The leaders of the groups may be be therapists from any of the disciplines, special teachers, social workers or others, all sharing an understanding of each other's fields and aims, and a real interest in the total development of each individual child. The programs are planned to give experiences that aid speech, emotional, physical, sensory and intellectual development.

Playgroups are conducted on a one-to-one basis, with one therapist leading the group, another assisting and each mother helping her own child but relating easily with the others. Activities are planned to overcome the area of delay, but emphasis is also on each mother and child sharing an enjoyable experience together (Hunt, 1983). The structured activities each week are planned around one particular sense: two or three weeks each term are spent on sight, hearing, smell, touch, taste, and body image, respectively. Each session includes singing (action songs, simple rhymes etc), vocalisation with movement, sensory stimulation, gross-motor activity and creativity. For the older group, there is usually some form of fantasy such as acting simple stories or dressing up, and sometimes a simple social game such as 'musical mats'. During the coffee and chat periods, mothers have the chance to ask therapists for advice with particular problems, such as difficulties with feeding, how to encourage use of hands, good positions for play, and can give each other helpful ideas gained from personal experience. While adults talk, the children have time for free play either inside with the doll's corner, building blocks and large equipment, or outside with the sandpit, water play and tricycles. It is deeply satisfying at these times to see the developing self confidence, imaginative play, increasing vocabulary use and social interaction of the children, and to feel that the playgroups contributed in some measure at least to these signs of healthy, happy childhood.

Camping Program: The camping program began in 1978, and like the other services, it developed in response to needs expressed by members of Noah's Ark Toy Library. The Program involves weekends and weeks away in a variety of settings, and the groups range from mildly to severely disabled children. There is always a high staff ration (1:1) so the children have full care and attention. All children on holiday, when things go well, have fun while developing their skills, testing their independence and their ability to get on with people in unfamiliar surroundings, while learning about new environments. Disabled children need to be able to do the same things as other children, though the nature of their disability and community attitudes make it much harder for them to have access to the same holiday situations. The camping program provides that opportunity, and gives them access to 'normal' experiences while ensuring they receive individual care.

Noah's Ark Toy Library has found that the camping program contributes to the physical, emotional and social development of the children who participate. The holiday camps give the children new experiences and challenges in a setting which is stimulating and caring, and enables them to develop their individuality, independence, and social competence. It is important to note that just as the camping program provides a holiday for disabled children, it offers a break to the families of the children, which is an alternative to institutional care. The break for families is guilt-free, since the parents have an opportunity to meet the staff and organisers, and know the nature and quality of the care the children will receive. They also know, after the first holiday, that their children are going to enjoy themselves.

Integration: Noah's Ark Toy Library aims to see disabled children integrated into the community. The range of its services facilitates that aim, by supporting parents and helping them to develop the potential of their disabled children through play, and by encouraging the whole family to visit the Library and join in. Siblings are welcome in playgroups, in hobby groups and on the camping programs, and that, in its own way, provides a model of the community at large. The aim is not to enclose disabled children in a restrictive environment but to develop their physical, emotional, social and intellectual skills in ways that will enable them, as far as is possible, to be included in the whole community. As part of that aim, there is now an integration officer who works with children and their families parallel to the camping program to assist children to move to community-based settings.

Sibling Groups: A number of writers have cited evidence of sibling disturbance in families with a disabled child (eg. Grossman, 1972; Kew, 1975). However, through our involvement with families and with conducting discussion groups and camps for brothers and sisters, it appears that not all are adversely affected. Like their parents, siblings are vulnerable to emotional and social stresses, and sometimes these affect their achievement, educational and social development. At times they need to share some of their feelings and experiences and to learn ways of coping with their peers who are in a similar situation. Counselling and discussion groups for siblings are available through Noah's Ark. Groups are held in a six-week block during each school term or as a one-day workshop during school holidays.

Switches Program: Through the switches program, Noah's Ark is developing opportunities for severely disabled children to gain some control over their environment. The switches are easily activated by slight movement or pressure; a lead connects to a battery-operated toy that lights up, moves or makes a sound creating a stimulating reward. As a result of this program, the beginnings of independence and choice are being shown by many children who previously had little or no means of communication. Because of the success of this program new ideas are being developed. Workshops for switch making and toy conversion are held each term and a Newsletter 'Which Switch?' enables everybody interested in these new developments to keep in touch with each other, share ideas and become aware of resources.

A Long-term Service: Because Noah's Ark provides comprehensive family-centred services for the child and young adult, parents are able to use the services over many years. Over time, a usage pattern has developed. Parents are seen most often during stressful periods; eg. at the time of diagnosis, at about 3-4 years when other children are entering kindergarten, and at puberty. Staff understand and are able to help with a range of difficulties, including those associated with stress, coping with visits to doctors, hospital appointments, broken sleep and distressing news about a child's abilities and potential. As the staff has a high continuity, long-term users of the service are known when they return again to use another facet of the Library's programs. In addition, the children and young people identify with the Library and, as the needs of the families change, the ongoing relationships keep Library staff and parents directly in touch.

Helping parents to work through problems, feelings, frustrations, acknowledging their child as a valued person, treating the family with respect, encouraging shared decision making, providing information on services and facilities, providing practical help and advice on methods of handling a wide range of play materials, are all ways the Noah's Ark Toy Library operates to encourage the development of positive relationships within the family. An improvement/enhancement of the cycle of family interaction affects all family members and provides the basis on which the child can reach out, play and be stimulated to reach his potential.

CONCLUSION

Noah's Ark Toy Library, which began in a small way in 1971, has grown in its membership and in the range of its services, to become the most comprehensive service of its kind in the world. The collection of toys available for loan is the focus of activities, which provide a unique degree of encouragement and support for disabled children and their families. From the structure of its committee of management, to the domestic residence in which it is housed, and the approach of its staff, Noah's Ark Toy Library is community-based, though it is part of the network of services available to disabled children and their families. Its flexibility and autonomy, combined with a lack of bureaucracy, has enabled the Library to respond directly to the needs of its members and to grow in response to these needs. It has provided a model for other organisations (toy libraries and older established services) and has been a catalyst in the formation of the Victorian, Australian and the International Association of Toy Libraries.

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PART 3

ISSUES IN EARLY INTERVENTION

Chapter 25

INTRODUCTION

Sandra Bochner

Over the past decade, early intervention has moved from being just one small component in a network of largely medically-based services provided for children who have specific sensory and physical impairments, to being an important element in health, welfare and education systems that provide a range of services, from birth, for children who are considered to be delayed or at risk of becoming delayed in some aspect of their development. The chapters in Part 2 of this collection provide examples of some of the changes that have taken place as early intervention has become an accepted part of the services provided for children with impairments and their families. These changes have included a move away from programs designed to serve biologically-based disability groups (e.g. children with cerebral palsy) to programs that focus on a specific aspect of development (e.g. language acquisition), a specific age group (e.g. infants and toddlers) or to programs that provide a resource that can be used across age levels (e.g. the Toy Library). The chapters in Part 3, the final section of this book, pick up some of the themes that were identified in the previous chapters, and provide an overview of the current situation, in relation to issues in early intervention, across Australia.

Five related themes recur through the eight chapters in Part 3:

1. Programs
2. Teachers
3. Parents
4. Integration
5. Evaluation

Each of these topics has been referred to in earlier chapters, but they are examined in more detail in at least one of the following chapters.

1. Programs

Issues related to programs, their content and efficacy, are major themes in the chapters by Leeson and Opolski; Leach, Swerison and Leach, and Thorncraft. Questions about efficacy of service delivery are addressed by Carter in his review of programs for children with Down Syndrome, and by Lewis and Ferguson in their case study of a program evaluation.

Leeson, in her discussion of the Developmental Learning Program from a professional's perspective, describes a program which was based on a 'consumer model', in which the service is adapted to the needs of participating families, in contrast to the 'expert' model of service delivery, where the family is 'shaped' to a predetermined program. This flexible approach undoubtedly has many benefits for families, as is acknowledged by Opolski in her report, based on her experiences as a participating parent. This is the only contribution to the volume that is written from the point of view of a parent, and Opolski highlights some of the adjustments that must be made by families following the birth of a baby with a handicapping condition. The needs of siblings are also considered in this paper which should be read by all professionals who are involved in the provision of services for children with disabilities and their families.

Thorncraft's chapter extends the now familiar debate about **manual** or **oral** communication systems to consideration of the relationship between total communication, or simultaneously spoken and signed English, with Auslan, the sign language used by Australian deaf adults. Thorncraft argues that, currently, Auslan is not recognised in schools in New South Wales as an appropriate language for deaf students. She cites evidence to show that deaf children of deaf parents (i.e. those who acquire language through an intact signing model) are significantly advantaged, educationally, when compared with their deaf peers who are born to hearing parents. Thorncraft suggests that children learn to communicate most effectively if they are able to interact with adults who can provide an intact or mature language model. Where an inadequate model is provided, as when hearing parents, who previously did not know sign language, pair signs with their speech, the children are likely to have problems in acquiring an adequate language system. One solution is to give the children access to experienced signers, particularly during the early stages of language development. The other is to teach Auslan as a first language using experienced Auslan users, with English introduced as a second language after the children have become competent in Auslan. Thorncraft then reviews the use of signs and speech with autistic children and distinguishes between the communication needs of these two groups of children. Finally, she lists some questions that should be addressed when decisions about the use of signs and speech are made for children who are likely to encounter problems in learning to talk.

Leach, Swerson and Leach's chapter provides a good example of a research-based service which sought to identify the most effective intervention model for teaching children with a range of intellectual impairments. Using a parent-training approach, they trialled three programs in order to identify first, their degree of effectiveness in terms of individual rates of learning; secondly, the extent to which they reduced parental dependence on professional support for ongoing programming; and thirdly, the relative cost-effectiveness of the three training models. The programs trialled included Distar Language, T.A.L.K. and the Popovich Behavioural Checklists. Subsequently, the latter two programs were replaced by Re-Ed, which was developed by Leach and Leach and provided a good initial program for children who lacked the prerequisite skills to enter a Distar Language program. It is interesting to read this account of the trialling and subsequent development of a program for use in a particular early intervention service. Clearly, this approach is a good model for the selection of an appropriate program in a newly established service.

Foreman's chapter is a really interesting one, in that it reviews some of the more controversial treatments that have been available, in Australia, for children with Down Syndrome. As one cure proves to be relatively ineffective in achieving the goals claimed for it, others seem to appear to take its place, and Foreman's chapter provides a good review of the efficacy of some of those that have recently attracted the interest of both professionals and the families of children with Down Syndrome. For example, the claims made about cell therapy have caused a number of families to seek this treatment for their Down Syndrome child and probably as many again would have tried the treatment if it had been readily available. Similarly, plastic surgery has been tried by some, but anxiety about the risks involved have prevented other families from exploring this procedure. It must be of concern to all involved in the provision of conventional services, particularly when the gains made as a result of programs are slow, that parents may turn to these non-orthodox solutions as a more effective alternative to the problems of their child. As Foreman suggests, it is easy to understand this reaction: such parents are not experts and must try any program that they believe will assist them. The role of the professional is to advise, to provide accurate information but it remains the right of all families to decide what treatment they will try. So reports such as that presented by Foreman are very useful, both for parents and professionals, so that an informed choice can be made about the type of program to be followed.

The chapters by Carter and by Lewis and Ferguson are written from a more distant perspective than those just described, in that they report on an external evaluation of a particular program (Lewis and Ferguson) and a review of published literature on programs for children with Down Syndrome (Carter). Lewis and Ferguson use a case study of a pilot program that provided a home-based service for developmentally-delayed children to explore issues in evaluation. Their discussion highlights some of the factors that should be considered when planning a new program; for example, criteria are needed to identify procedures related to referral, assessment and curriculum, as well as staff development, co-ordination with community resources and aspects of program management. Carter, on the other hand, identifies five broad categories of program types that were located in a survey of the literature on early intervention for children with Down Syndrome. Examples of each type are probably to be found in the program descriptions included in Part 2 of this collection. Carter reviews the claims for efficacy made for each program type and makes some suggestions about the relative effectiveness of some of the approaches examined in his review.

2. Teachers

One of the most critical variables in any early intervention program is, of course, the staff that provide the service, and over the last decade, a major change has been the addition of teachers to the team of professionals that provide intervention services. So it is interesting to read Campbell's report on developments in the area of special education within teacher training programs in early childhood. She sets her report on current training programs in this field in the context of three themes: first, the concept of the 'whole child' and normal child development as a basis for planning intervention services; secondly, the teaching process, as it has developed within traditional educational settings, and its relationship to programs provided for younger children in home or preschool settings; and finally, the role of the teacher within programs implemented in a variety of settings, often under the responsibility of non-educational (i.e. health and welfare) agencies. Clearly, the training of educators to work within these varying settings and programs presents a challenge to traditional teacher training courses. Similarly, the needs of early intervention programs, in terms of the contribution that can be made by appropriately trained staff, particularly teaching staff, need to be fully explored and understood if teacher training programs are to respond to the demands for the appropriately trained teachers to work successfully within the various types of early intervention programs that are now available in our communities. However, as Campbell correctly points out, the field of early childhood special education has developed, in this country, as a result of parental pressure and ad hoc community responses, as is evident in many of the program descriptions included in Part 2. Teachers have often worked in this area because of a moral commitment to the children, and have developed their skills on the job. Perhaps it is time for a more consistent approach to be taken, particularly in relation to the provision of effective teacher training for staff working in early intervention programs.

3. Parents

As noted by Pieterse, in her introduction to Part 2, one of the major themes to emerge in early intervention has been the recognition of the valuable contribution that parents can make to the programs provided for their children. So it is of benefit to have Leeson and Opolski's chapter which presents the viewpoint of both a parent and a professional who have worked together on an early intervention service located in South Australia. No doubt, many of those who work in a professional capacity in early intervention are, in their non-professional roles, both parents and home-makers. Yet in spite of this shared background experience, it is probably almost impossible for those who have not had a child with a serious developmental delay, to fully comprehend the impact of this event, on parents, siblings and the wider family. Following early evaluation of intervention programs for children who were educationally disadvantaged (e.g. Headstart in the U.S.A.), educators came to realise the importance of both involving parents in an intervention program and, where possible, using parents to implement teaching objectives. Results showed that parents, with their dedication and knowledge of their child, could achieve program objectives at least as well as, and in some cases more effectively, than the professionals who guided them. However, in harnessing this energy and commitment, professionals sometimes failed to recognise either the extent of the burden that they added to those who were already under stress, or the need for counselling and support for families that were, in some cases, still trying to come to terms with the birth of a handicapped child. Opolski's contribution to this collection is important because it highlights the needs of families in early intervention and Leeson provides a useful complement, in her report, from the professional's viewpoint, on the operation of the Developmental Learning Project. The themes raised here are echoed in earlier chapters, such as those by Bull, Gibson and Morrish, and Farrell and Glue. Early intervention can only profit from the focus that these chapters give to the needs of parents, as well as children, for high quality and appropriate services.

4. Integration

Much of the current debate in Special Education in Australia is concerned with issued in integration. So Kenny's paper is appropriate, with its focus on the factors that contribute to successful integration. The program that she describes clearly provides a high quality service and the guidelines set out in this chapter give a useful basis for any initiative in this important, but still developing area. The impact of Nirji's call for 'normalisation' of services for the handicapped has had a profound effect on program development in this country, but the procedures that can be used to achieve this goal successfully, are still being identified. Some examples of successful integration projects are also included in a number of the chapters in Part 2.

5. Evaluation

While it can be claimed that early intervention is now regarded as a 'motherhood' issue in Australia (i.e. the program is accepted as a generic service that does not need to be justified), questions about evaluation and efficacy remain. Lewis and Ferguson summarise some of the major reasons that can be cited to support the need for ongoing evaluation in early intervention, such as the need to identify effective teaching procedures and the need to ensure that resources are used efficiently. They use their review of the LEEP program in N.S.W. to exemplify how they established priorities for the many questions that, it was felt, should be asked, and how they determined what data should be collected in order to evaluate the operation of the program. Some of the major constraints that can limit such an evaluation are described; for example, ethical questions about the use of a contrast or comparison group, the problem of deciding how progress would be assessed, and what constituted a satisfactory level of progress for various groups of children (e.g. those with severely handicapping conditions). In contrast, Carter's paper approaches questions in evaluation from a more academic standpoint. He reviews some of the factors that can threaten validity, as when gains result from maturation alone, rather than intervention, or when results are not replicable in other settings, or with other staff. He reviews some of the major types of research designs that are used in evaluative studies in early intervention, such as quasi-experimental studies using post-test scores only, or those using non-equivalent control or contrast groups. A very useful summary of a number of studies, including two Australian programs, is included and Carter discusses that strengths and weaknesses of these various approaches to demonstrating efficacy. He concludes that claims for program effectiveness appear to be supported by research but argues strongly for more replication of effective programs, and better designed studies that will permit the identification of the specific components of programs that contribute to the gains that are observed. It must be hoped that Carter's call for further, well-designed research will be noted and more reports about successful Australian programs will be made. It is interesting to ponder where these reports will be published, if they are to be accessible to everyone involved in this rapidly developing area.

Chapter 26

PARENTS AND PROFESSIONALS; A WORKING RELATIONSHIP

Judith Leeson
Judy Opolski

This paper will present some aspects of an early intervention program which was established through parent initiative, and which has continued to evolve in response to parent need. Some of the issues raised in the first section of the paper relate to the need for family focused services and the difficulties experienced by many parents in their relationships with professionals. Some of the competencies necessary for professionals working with parents have been or are continuing to be addressed in the Program that is described in the second part of this report.

I. A PARENT'S PERSPECTIVE

The recent trend towards parents and professionals working in partnership to provide early intervention for intellectually handicapped children is one which is gaining momentum and credibility. The resultant sharing of skills and information allows for intervention to be carried out more effectively by providing parents with the skills necessary to integrate intervention strategies into the normal home and family routine. There is scope within such a partnership for the professional to provide not only information but also support to the parent and the whole family thus fostering a healthy accepting family atmosphere for the child's development. Professionals in such a partnership will require many skills in addition to a competency in their own field. Counselling and family support skills are vital to ensure good communication with the family. This paper will discuss the many areas which contribute to a successful parent professional relationship and the implications for the professional who undertakes to incorporate counselling and family support into family intervention.

The birth of a baby is a time of enormous change and readjustment for all parents. Their reactions to their new situation will depend on many factors; the difficulty or ease of the birth, whether the child was planned or unplanned, previous parenting experience and possible transient or prolonged post-natal depression, stresses of routine, sibling needs and expectations for the child and themselves. A diagnosis of a handicapping condition at or soon after birth disrupts the initial adjustment for a considerable time as parents experience the grief, anger, sorrow and perhaps guilt which often follows. They may feel very uncertain about the requirements for parenting a handicapped child, how the child will affect their family life and have many fears about their child's future. At this time parents are worried and confused and may feel that they are no longer in total control of their own and their family's future.

A common reaction to the feelings of helplessness, inadequacy and despair is a feeling of the need to 'do' something. For many parents an early intervention program provides the opportunity and the encouragement to do something positive and constructive towards helping their children — and in the process, themselves. But the decision on whether or not to participate in such a program is not simple or clear-cut: there are the practical considerations of time, effort and the effects on family life, and the moral considerations related to doing one's utmost to try to reduce the impact of the child's disability. The practical concerns are relatively easy to deal with, but morally there really is no choice at all. If a family does not take advantage of the opportunities offered through an early intervention program they may always feel that they have denied their child a chance to fulfil his potential. It is not uncommon for confused and anxious parents to feel pressured by well-meaning family and friends — 'so much can be done for these children now' becomes more of an ultimatum than the encouragement intended. For many parents the decision to participate may be less the result of calm consideration than an emotional response to the need to 'do' something, and so regain control, and affirm their capabilities as positive parents. An early intervention program is seen by some as providing the 'cure' to make the child well, or normal. For others, the fact that they have had to look beyond the family for help is not only a reaffirmation of the child's condition, but also of their own feelings of inadequacy. This all adds up to the difficulty of accepting the child, and bringing him into being a full member of the family.

EARLY CONTACT WITH PROFESSIONALS

Parents face major readjustments in their relationship with their handicapped child and their own emotions. Furthermore, if they subsequently become involved in an early intervention program they will encounter situations to which they must adjust. The techniques and strategies suggested may conflict with their own parenting methods and it may take considerable time to feel comfortable and less defensive. It will be necessary to work with professionals and, while appreciating their assistance, parents may paradoxically resent the necessity and may feel that it threatens their competence as a parent. They may feel that their rights as parents are threatened by someone else taking some of the responsibility for their child's development. There may be a conflict between their need for assistance and their desire to assert their rights as parents. Many parents have expressed the feeling that their child becomes 'public property' with many people interested and involved in his development. This puts parents in a position where they may feel that their skills are being examined critically when, normally, the parent child relationship is a very private one in which few other people are involved.

The two models of service delivery, home-based and centre-based both involve stresses on the parents and family. If the child is receiving services in the home, such as those provided by the S. A. Government agency, The Intellectually Disabled Services Council, the mother's need to present a 'coping' appearance may involve frantic cleaning and tidying in order to present a spotless house as a reflection of her abilities. Scheduling appointments around the child's feeding and sleeping and the family's routine may not always be easy and for some people the stress of having a relatively unknown person in the house can be enormous. The alternative is to attend services at a centre and this can also be very difficult for many parents initially as it means taking their needs and problems out of their private arena and to some extent making them public. Parents may be very hesitant about meeting people and yet they must take responsibility for making contact. They may also be reluctant to encounter other handicapped children. It can be a real venture into the unknown for parents as they will not know what to expect nor what will be expected of them. There may be additional ongoing stresses; transport to arrange, childcare to organise or siblings to take along and cater for.

While most parents will eventually discover and value the benefits of early intervention, there are many factors, both personal and practical, which will affect the relationships established between themselves and professionals. It is not unreasonable to expect that professionals must be not only well informed and competent, but sensitive to individual family situations in order to lessen the stress of initial contacts. It seems reasonable that parents should take some responsibility for the successful establishment of that relationship but it must be acknowledged that parents in a state of emotional turmoil may lack the confidence and interpersonal skills necessary to do so and the responsibility must initially lie with the professional.

FAMILY FOCUSED SERVICES

Effective intervention must involve more than simply a concern for the developmental progress of the child. Sincere cooperation between parents and professionals can benefit other members of the family as well as the handicapped child. The emotional climate in which the child lives will greatly affect his development as the stresses on the family will dictate its ability and willingness to be involved. A stressed and disturbed family needs support to resolve problems in order to provide a relaxed positive environment in which the child can learn. The needs of individual family members may be critical in their own right and deserve attention as such, not just in relation to the effect they will have on the handicapped child.

Professionals should regard their responsibility as extending to the whole family, particularly if their involvement is to be long term. The fact that most services are provided during work and school hours makes it impossible for the needs of every family member to be responded to on a regular basis. Professionals must take time however to become aware of family dynamics and stresses if they are to provide emotional and practical support. Good communication between the parent and the professional is essential if support needs are to be identified and responded to. This should be an integral part of the partnership established. Parents should be aware from the beginning that the professional is available to provide general support not just to 'work' with the child. This may involve supplying the parent with relevant literature, information on support and respite services and above all allowing plenty of time for the parents to discuss any issues, personal or practical, which concern them.

There are many aspects of a successful parent professional partnership and, as mentioned previously, open communication is a vital factor. There must be a sincere respect for the family situation by the professional and trust between the two if problems, both in the child's development and within the family, are to be identified and addressed. The openness and trust necessary will evolve gradually as the parent and professional get to know each other better and appreciate each others skills and qualities. Decisions about the child's developmental requirements and programming may be a cooperative effort by both parties or made by one or the other depending on the parent's emotional state and ability to be reasonable and objective at any given time and the nature of the problem. There may be times when the parents' intuitive response to the child may be the critical factor in decision making. At other time the professional's knowledge and expertise may define the problem in a manner which the parent, who is unable to distance herself, may not see as clearly. The responsibility of both partners will change with circumstances. Flexibility and a willingness to work in true partnership and consultation with respect on both sides can result in effective and beneficial intervention and family support.

Siblings have particularly important needs as they face not only the normal displacement and jealousy felt by most children when a new baby is born but also additional stress if the handicapped child appears to be receiving extra special attention from a range of people. Siblings may have many concerns and fears relating to the handicapped child and to their own position which require recognition and sensitive handling.

The needs of siblings, if they are present during a sessions, must be acknowledged and responded to as much as possible. If siblings are not given adequate time and attention, any benefit the handicapped child and the parents may receive from the sessions is likely to be undermined by extra stress on the whole family because of behaviour the sibling may display due to resentment and jealousy. Siblings have rights and needs too, and these must be respected. Time during initial sessions should be allocated very flexibly, perhaps 25% for the handicapped child, 25% to reassure siblings of their importance and 50% for general and/or specific discussion with the parents. While it is important for professionals to share their skills with parents to enable effective intervention to be carried out at home, it is also vital that adequate time is allowed for discussion, reassurance and readjustment. The child's future happiness and development will greatly depend on positive family interaction. This interaction can be facilitated and encouraged by professionals recognising and, as much as possible, meeting the needs of the whole family.

A problem which many parents express soon after discovering that their child has an intellectual handicap is where to draw the line between acknowledging their child's special needs and treating the child as normally as possible. Another issue is how much extra time should they give the child, possibly at the expense of their other children.

These issues may be the most important factors in determining how the child is accepted within the family. The child's needs must be met but the family equilibrium must also be maintained. It is very easy for parents to be so concerned for the needs of the disabled child that their own needs and those of other children are overlooked. Family focused services can help to facilitate a practical and beneficial approach by not focusing solely on the child. Such a model can help set the tone for the family by recognising that while the child has needs which require special help, all members of the family are equally important.

Clearly, the provision of services directed towards the whole family will have many implications for professionals. The philosophical base of the service provider should include provision for information-sharing on a wide range of topics and the opportunity for support to be available for the whole family. This may involve reallocation of time to allow for longer visits or sessions and ideally would provide the opportunity for out of hours visits to enable fathers and siblings to benefit as well. There may well be a need for changes in attitudes and policies by administrators to enable the inclusion of support services as well as hands-on intervention. There will be a need for willingness on the part of the involved professionals to incorporate skills and responsibilities in their approach for which they may not have received training. Currently there is a deficit in the training of professionals, such as physiotherapists, psychologists, special education teachers, etc., in that they are not trained in family counselling skills. There should be opportunities for professionals interested in early intervention to acquire these skills during their training. Alternatively, the agencies providing services should provide preservice and inservice instruction in this area.

SUPPORT COUNSELLING

It is difficult for parents to communicate their feelings to anyone during the grief and readjustment processes and it can be particularly difficult to be open with professionals whom the parent does not know well and who, by virtue of their status, seem remote and possibly intimidating. For this reason it is particularly important that professionals are trained in family support and counselling skills. The various stages and emotions which parents experience indicate varying levels and types of support counselling and information sharing. A trained social worker or therapist may be appropriate in the initial stages and if significant problems continue to be apparent. There may be a need for a central person to coordinate services and help parents make decisions about the child's future.

The need for ongoing emotional support can certainly be attended to by the professionals involved in the child's early intervention program. This indicates a need for a long term involvement for professionals to establish open, trusting relationships. If the parent is encountering different professionals every few months there is no opportunity for the necessary intimacy and depth of knowledge to evolve. The professional who knows the family situation well is able not only to provide practical advice on problems and delays but can also help the parents to cope with any family stresses resulting from the situation. Initially the professional may need to encourage parents to discuss their feelings and air any problems. As the parents' confidence and trust in the professional grows they can take more responsibility for communicating their emotions and ideas.

Professionals must be very sensitive to the changing nature of the parents' emotions and able to recognise efforts the parent is making to communicate their feelings. The nature of the parent/professional relationship is dynamic and changes to it may be very subtle. Counselling skills enable the professional to be aware of these changes and capitalise by establishing deeper and more open communication.

SUMMARY

Parents face many difficulties in learning to adjust to having a handicapped child. In emotional terms it can be a long hard struggle to accept the child's disabilities and total acceptance may never happen. Early intervention and special education continually reinforce the child's need for special help and the parents' apparent inability to cope alone. Professionals who provide effective intervention strategies and sensitive support to the parents can assist them to feel confident in their role of positive competent parents.

The birth of a handicapped child affects the whole family and it is vital that this fact be recognised by agencies offering early intervention services. The child's acceptance with the family, his acquisition of skills (determined as important by the family) and the child's self image (particularly not seeing himself as too 'special') can be assisted by services recognising the importance of the needs of the whole family as well as providing intervention.

The relationship established between parents and professionals has many factors contributing to its success. Mutual respect, trust and a willingness to learn from each other are vital, and good communication the most important of all. The evolution of good communication is assisted by professionals who are equipped with the skills necessary to prompt parents into talking openly about their feelings and problems. When parents expect to receive empathy, sympathy, sound advice and practical solutions they are in the healthy position of being able to work through feelings and get practical assistance when necessary.

The needs of all family members should be viewed in their own right as well as in relation to the effect they may directly or indirectly have on the handicapped child. Clearly, the professionals providing intervention have a unique opportunity to recognise and help resolve family problems related to having a handicapped child in the family. Early intervention has evolved from one to one intensive teaching by professionals to genuine parent professionals partnership utilising the unique experiences, insights and skills of both parties. Clearly the provision of support and practical assistance to the whole family is the next step in that evolutionary process. While there are many aspects of family focused support services which need attention the successful establishment of such services is not only desirable but possible.

II. A PROFESSIONAL'S PERSPECTIVE

The Developmental Learning Program offers parents of young children with Down syndrome the opportunity to work in partnership with professionals to enable them to provide family focused, home-based intervention from birth. During the early years the influence of the family is recognised as being of prime importance in stimulating development and in adapting the environment to meet the needs of each family member.

Families are able to attend the Developmental Learning Program once each fortnight in small groups with children of similar age for support, information, developmental assessment, and individually planned programs to carry out at home if they wish. Parents are able to have individual discussion time during each session with the special education staff, who are able to offer professional support and assistance. There is also the opportunity for parents to spend time with each other during the session, and this is seen as an integral part of the Program where support networks are developed informally and many enduring friendships have their beginnings.

The rationale for this model of service delivery is based on the results of action-oriented research by professionals in the Program, direct input into the philosophy and practice by parents, the willingness and ability of the staff to move away from more traditional teaching methods, and is supported by research from educational, medical and social sciences. The acceptance of a 'consumer model' (Cunningham, 1982), in which services are developed to suit the needs of the family, rather than shaping the family 'through successive approximations' to fit the service, has been made in preference to the 'expert model', in which the professional delivers direct services to the child. These 'expert' models of service delivery include varying degrees of parent participation and involvement, ranging from the accidental to the essential, and may be appropriate at various ages and stages of the child's development provided they meet the needs, not only of the child, but of the family as well. Parents and professionals who work together with young children with developmental disabilities share many common skills and attributes, and have many common goals. However, each may also contribute some specific abilities, knowledge, and motivation, which may be used in a complementary way in a partnership.

All parents who come into the Developmental Learning Program bring with them valuable life experiences, skills and knowledge which deserve respect, and which will, in part, determine the quality of life which their child will enjoy. Their ability to organise their environment, adapt to change, and learn through experience will be a significant factor in influencing their child's potential for development within a stable and secure family, utilising information and resources, and acting as advocates for further services. The long term active involvement and commitment of parents, can ensure continuity and provide motivation for home-based intervention, and quality interaction may occur among all members of the family in the most natural environment, and at the most opportune times. Parents have a unique opportunity to know their child, to be sensitive to his moods and levels of development, and to observe his spontaneous behaviour under many different circumstances. They also have the expectation that they will continue to learn parenting skills which will contribute to their effective management and pleasurable enjoyment of their child or children. Parents have strong emotional ties with their child which will influence their interactions within the family and the community, and they have both the desire and the right to make informed decisions which will have a positive influence on their child's life. These qualities, and more, make parents uniquely suitable for being intervention agents for their child with developmental disabilities.

These attributes common to most parents may be complemented by the special skills, knowledge, and personal qualities of the special education staff in the early intervention program, who will work with parents in a relationship based on mutual respect and equality (Mittler & Mittler, 1982). Special educators will need to contribute their detailed knowledge and experience of child development and of children with developmental disabilities, as well as some of the preventative measures that can be taken to mitigate some of the handicapping effects. They will also need to understand some of the learning difficulties which may be experienced, the range of techniques and strategies available to facilitate learning, and have the ability to assess, plan, and evaluate individual programs. It is essential that staff members have some knowledge of family dynamics, and that they have the capacity to respond to the unique qualities of each family. Basic counselling skills detailed by Cunningham and Davis (1985a) include good communication skills, competence in the field, understanding of the responsibilities and values within the model, respect for the family, attending skills, and empathy.

The crisis which occurs, and which is the catalyst for seeking support and information from hitherto unknown professionals, is the birth and diagnosis of a child with developmental disabilities. The contacts during pregnancy and confinement are mainly with the medical profession, whose expert advice is often sought and followed by the family, and in particular by the mother, in her role as 'patient'.

For most parents the birth of their baby is awaited with heightened feelings of expectancy, and these feelings are acknowledged in the colloquial terms used to describe pregnancy — 'expecting', 'anticipating', 'looking forward to the happy event'. It is a time of anxiety and excitement, when past experiences and knowledge are utilised to predict future events, and to make inferences about unknown factors which may significantly alter the lives of those involved. The prospective parents may wonder about the sex, personality, intelligence, health, and appearance of the coming child. Within their own value system they may express concerns about possible changes in the relationships between husband and wife, the increased responsibilities, and their abilities to cope, the changed interaction among themselves and other children in the family, and the need for future reorganisation. It is during pregnancy that the mother begins to feel attachment to the baby, and to enjoy his responses to her and the environment. (Brazelton, 1981)

The delivery of a baby is the culmination of these experiences and is usually a time of great joy and relief, followed by a period of readjustment and adaptation to the new baby and the changes produced by the birth. The separation of mother and baby at birth may interrupt the bonding process, particularly if the delivery is difficult, but the process should continue unless there is a crisis.

The birth of a handicapped child is a time of crisis, and the immediate reaction of parents to an early diagnosis is one of shock which may manifest itself in 'emotional disorganisation, confusion, paralysis of actions, disbelief, and irrationality'. (Cunningham & Davis, 1985b). This phase may be followed by reactions which are similar to those following bereavement, and be expressed in anger, resentment, and denial, or other strong emotions. It is important during this stage of grief that parents receive some counselling, as they need to know that these reactions are normal, and a way of assisting them to explore all aspects of the situation. However, failure to work through these emotions may hinder the processes of attachment to the child, and the parents' acceptance. During this period of intense reaction some parents may wish to have contact with another parent of a child with a similar disability. The sense of isolation, powerlessness, inadequacy to deal with the present and fear of the future may be alleviated, to some extent, by knowing that other parents have survived this crisis, and are offering empathy and support.

During the period of adaptation to their situation parents begin to ask for accurate information about the condition, and possible sources of assistance, later moving into the 'orientation phase when they begin to organise, seek help, establish new routines, plan resources and learn new skills' (Cunningham & Davis, 1985b). Models of the grief and adaptation process all highlight possible reactions, and the fact that every parent has his or her own unique response to crisis. Many will move through this to acceptance in a relatively brief time, but most will experience reccurring and intense emotions even after they have fully accepted their child. The term 'chronic sorrow' used by Olshanky (1962), has profound meaning for parents who are also aware that 'while it is a normal reaction to having a handicapped child, does not prevent parents from gaining satisfaction and pleasure from the achievements of their child' (Fortier & Wanlass, 1984).

Professional contacts during this time of crisis are possibly consistent with previous experiences, although there are a number of variables affecting these relationships, including the manner of delivering the diagnosis and prognosis, the sensitivity of hospital staff, support between parents and from within their family, and the existence of serious and possibly life-threatening medical conditions. There is often little time for grieving, and if the parents fear that their child is 'different', the process of bonding and attachment may be considerably interrupted or delayed. The parents' decision to seek information about possible help and support is an indication of their adaptation to the crisis, and should be acknowledged as a brave step into the unknown. Although many agencies providing early intervention services argue for the first and subsequent consultations to be in the family home where parents are able to control the situation, this is not always feasible, nor desirable, and there is much anecdotal evidence from parents in the Developmental Learning Program that, initially, these visits may be seen as an intrusion of privacy, and increase the sense of isolation and sense of 'difference'. In our society it is quite 'normal' for parents to take new babies to health clinics and for medical assessments; centre-based services are part of the Australian culture.

Parents are able to refer themselves to the Developmental Learning Program at any time after the birth of their child with Down syndrome, and make an appointment to see the Director, who becomes their first, consistent contact. Ample time is allowed for any number of appointments while parents gain information about services, about the implications of disability, and are able to express their feelings in an accepting environment. Parents need the reassurance that their baby will be responsive to them, and that they will be able to accept some of the responsibility for his or her development, have the ability to make informed decisions, and be capable, competent and independent. Parents are able to express their concerns about the effect of the disability on members of the family, about their ability to participate in the Program, and the possible outcomes of early intervention, and may observe several sessions before making any decision to participate. They are invited to attend together if possible, and with any pre-school siblings, in order to avoid having the focus on the child with Down Syndrome or having to make child care arrangements. Members of the extended family are also invited to attend at a convenient time for information, support, or observation. During these early visits, opportunities are made to confirm that the newborn baby is capable of eliciting genuine interest, pleasure, and admiration, and that parents are given positive feedback about their nurturing behaviours. If these appear to be significantly absent, some incidental modelling will often produce an imitative response. Every effort is make to reduce stress during these visits, and parents are exposed to as few staff members as possible to avoid being overwhelmed.

Most parents are eager to join in group sessions, especially if they have observed other parents and staff interacting in a relaxed, happy and constructive way. Sessions are staffed by two special educators, an assistant who is trained in mothercraft, and a physiotherapist; a maximum of five families attend. Mothers usually participate but there are many fathers who come whenever they have the opportunity, and some parents alternate. As preschool children are welcomed and have many exciting activities planned to meet their needs, session times are particularly busy. The emphasis in early sessions is on establishing relationships between staff and parents, and responding to the individual needs of parents for support, information and practical activities to carry out at home. The quality of interaction between parent and child is seen as a critical factor in facilitating early development during this period of maturation and of more significance than items on a developmental checklist of early infant behaviours.

Although many parents have accepted their baby before they come into the Program, there are those who have received little or no counselling to enable them to express their feelings and work through them. It is obvious that, for a number of parents, particularly fathers, there has been traumatic disruption to the process of bonding and attachment which will seriously hamper their emotional development, and their ability to accept their child.

The research on bonding and attachment in normal infants, and its application to children with Down Syndrome, is utilised in the Developmental Learning Program to assist parents in their early interactions with their child, and also to help them become more skilled in observation, which is the basis for later assessment and developmental programs. Bailey and Wolery (1984) cite the early work of Bowlby, on his studies on attachment, and state that 'the first social relationship a child establishes is with his parents'. This lasting bond is critical to the formation of future relationships, and it is based on mutual reciprocity. Berger and Cunningham (1983) observe that the newborn infant demonstrates an amazing capacity for attending to positive stimulation in a predictable manner, interacting with his environment. During the first few weeks of life the baby has a limited number of 'signals' which not only assist him to survive, but which enable him to get feedback from his own actions. His ability to elicit responses from his parents, particularly his mother, serves to strengthen the bonding process. Cunningham, in his paper on early social interactions between infants with Down syndrome and their parents, quoted his earlier research which shows that there is a delayed onset of such important signalling behaviours as eye contact, smiling, and vocalisation. In a controlled group, mothers of children with Down syndrome were found to make more efforts to gain responses from their child, but were allowing insufficient time for the child to respond. This had a cumulative effect of limiting the child's opportunity to respond, while contributing to parental anxiety. As parents became more responsive to the signalling behaviours of their baby, they were able to provide an appropriate level of stimulation which was not overwhelming. Parents can develop sensitivity to the changing states of their baby, and as they synchronise their responses to allow the baby the opportunity to attend and gradually become more competent, both are consistently reinforced by their own success and that of each other. Parents who continue to be over-anxious and too directive in their relationship with their child many stifle independent action and the development of the child's autonomy.

Staff input in this area must be sensitive and timely, reinforcing parents without patronage so that they gain in confidence and skills. During the first six months professionals are available as facilitators and a source of information, as well as acting in a counselling role. They are able to model specific handling techniques, and the assistance of the physiotherapist is very valuable during this period to provide assessment and therapeutic strategies for those children who have special needs in this area. Staff are able to offer practical assistance with feeding and sleeping problems, baby massage, and specific activities that are developmentally appropriate. Special attention is given to siblings during each session, and parents are able to observe many simple age appropriate activities for these children as well. During this period as attachment grows, so does acceptance, and parents gradually come to feel that they are able to meet the needs of their developmentally disabled child without too much reliance on professionals. Parents, through their contact with each other, the staff, and other members of the community lose their sense of isolation and inadequacy, and begin to feel confident and competent. If the aim of attachment is detachment in early parent-child relationships (Brazelton, 1981), then the aim of any early intervention program should be similar, so that increasingly parents are able to feel a sense of independence and the ability to deal with the problems of their child and, indeed, the whole family, in a capable, informed and assertive manner.

As the needs of the family and the child change, so do the structures and content of the Program, but within the philosophy that the child's early needs may be best met within a family, who not only are able to make informed choices about home-based intervention, but who are also going to be able to accept the responsibility for those choices as do other parents.

The effectiveness of the Developmental Learning Program in minimising some of the difficulties and obstacles faced by parents in the period following the birth of their child with Down syndrome varies from family to family, and depends on many of the factors outlined in this paper. All parents adapt over time to the changing skills, behaviours, and personality of their children, and are not required to demonstrate 'life long' acceptance at birth. The process of acceptance, and the growth of attachment may be life-long however, and each member of the family will adapt in a different way, and within different time frames. Parents who are involved in the Developmental Learning Program may continue until their child is in the second year of school, but obviously the degree of involvement will change. There is time for parents to share, to learn, to read, to teach, to give and receive support within such a Program, as partners. As their knowledge, awareness, and involvement in the Program increase parents are able to have direct input into the overall directions of services, and effect changes in service delivery. Many of the deficits in the Program are acknowledged by the partnership, but are a result of economic and time restraints, others are influenced by the increasing numbers of families seeking this service and the policy of unrestricted entry. Some deficits are a result of inadequate training for special education staff in the counselling area, and many a result of our imperfect knowledge and skills in the fields of special education, and preventative measures in bio-medicine. However, in a partnership, when both parents and professionals are able to have open and honest communication, there are many avenues for overcoming problems and for giving feedback to each other on a constructive basis.

All parents and professionals who are involved in early intervention have a unique challenge to become more accepting, more sensitive, more creative and to expand knowledge about what it means to be human through their contact with children who have developmental disabilities.

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Judy Opolski.

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Chapter 27

TEACHING PARENTS TO BE DIRECT INSTRUCTORS AND CHILD ADVOCATES: THE PARENTS AS EDUCATIONAL PARTNERS (PEPS) COURSE FOR PARENTS OF INTELLECTUALLY HANDICAPPED PRESCHOOL CHILDREN

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Hal Swerissen
Pauline D. Leach

A large number of studies have shown that early intervention for children with intellectual disabilities is likely to be more successful if parents are involved as trained teachers or therapists(e.g. Rees, 1982: Harris, 1983). Indeed, it can be argued that, without full parental involvement, the long-term success of early intervention is greatly jeopardised. Yet, for the most part, efforts by Government agencies to involve parents as active, equal partners have been sporadic and ad hoc. Many parents still report that professional services for their children are paternalistic, dependency-forming, superficial, de-skilling and even devaluing. Too many parents still seem to find themselves on the merry-go-round of assessment and diagnosis only to be left frustrated in their request for clear, long-term guidelines as to what to do to ameliorate the problems they face. There are also continuing problems when services have seriously planned to involve parents. Training effects, for example, are short-lived and there are few attempts to maintain parent involvement over long periods to ascertain their impact on children's development.

With these observations in mind, we began a training course in 1982 which a group of five parents of young, disabled children had asked us to design to teach them to be effective home instructors. In collaboration with them, we were to help them prepare for and develop a long-term, systematic instructional program that would cover a range of communication, cognitive and academic skills required by their children to optimise their participation in the family, school and community.

Inevitably, the choice of beginning skill areas was determined by the existing skills and ages of the children concerned. Thus the prime focus for the younger, more handicapped children narrowed down to skills such as paying attention, making discriminations, and imitation, whereas, for those who already had these skills, the focus was on receptive and expressive language with or without speech. The ultimate goal was to plan a path for the parents that would in time enable them to move on to other areas of academic development such as reading, maths and spelling, if and when their children reached the primary school stage.

After we had run the first course, other parents of developmentally disabled children requested similar training and a repeat course was offered. Subsequently, courses have been requested regularly until, in 1988, we have reached a point where over 100 families have participated. Throughout this period, there has been no formal selection of families. Parents typically have heard of the training course from others, or from local service agencies, and have then been invited to an initial meeting where details of the course, its timetable, methods, goals, materials and costs have been fully presented. Their final selection has been simply on the basis of their wish to participate.

In this chapter, we will describe the training course and present evaluation data on its effectiveness across the sub-groups of parents of preschool and early primary aged children who have focused mainly on preschool cognitive and communication skills.

THE PARENTS AS EDUCATIONAL PARTNERS (PEPS) COURSE

1. Course Assumptions

From the outset, we were concerned to develop a training program that would provide parents with the expertise and motivation to maintain their involvement as instructors of their children over the long-term. Intellectually disabled children require as much time as can be arranged in individual instruction if they are to accelerate their rates of learning. So too, they need high quality instructional programs that are relevant to their particular developmental goals and finely stepped to keep them on developmental tasks that are at the correct level of difficulty. According to research, these three factors of time-on-task, relevance of task, and appropriate level of difficulty, combine to form a strong predictive variable of achievement which has been called 'academic learning time' (e.g. Fisher, 1978; Smyth, 1980). Secondly, we wanted to develop a course that would reduce parents' reliance on professional support for continuing programming. We wanted to 'enable' them to make their own decisions about programming and their children's needs and, ultimately, to gain a sense of personal control, worth and value in managing their children. Finally, we aimed to design a cost-effective course that could be run as a regular unit in a range of services offered by community agencies.

2. Course Aims

Following from our general aims and orientation, the objectives of the PEPS course has been to teach parents to master techniques for delivering instructional programs to their children and for maintaining their efforts as instructors over the long-term. We have also aimed to increase the advocacy skills of parents to enable them to make full use of, and possibly exert a positive influence on, the services provided. More specifically, we have taught them the following skills:

- How to deliver pre-designed, pre-scripted, behaviour-based programs for teaching cognitive, language, and communication skills (and later, reading, spelling and maths) to their children.
- How to use behaviour management procedures to ensure their children's optimal attention and task engagement on the programs.

- How to generalise and maintain their children's skills learnt on the programs through incidental teaching in the natural environment.
- How to prepare for and maintain their efforts as instructors over the long-term.
- How to be effective advocates for their children, particularly in the education system

3. Course Design and Content

The overall timetable of a typical PEPS course is presented in Figure 1.

The course covers a four-month period and includes five to ten families per course. Potential participants are first invited to an open meeting, during which all details of the course are given, before they commit themselves to participate. This ensures an understanding of course objectives, materials and methods and allows participants to decide whether or not these are congruent with their needs, time availability and, to a certain extent, their philosophies of child rearing. Families are invited to choose any number of people (e.g. spouses, friends, volunteers, etc.) to attend the training course with them. Once families decide to participate, an initial assessment of their child is carried out by a psychologist to place the child in an appropriate teaching program and to provide pre-course measures of development. The assessment instruments used for language development have been Developmental Profile II (Alpern, Boll & Shearer, 1980), the Reynell Developmental Language Scales (Reynell, 1977), and Assessing Language Skills in Infancy (Bzoch & League, 1971). All details of a child's assessment are discussed fully and openly with the parents.

Subsequently, the parents, plus any number of others interested in working with their child or who wish to provide support, meet as a group for five, weekly two-hour sessions without their children. The sessions take place in the evening to allow as many to attend as possible. This means that there may be a much larger number of people in attendance at any time than the parent teachers of the families currently completing the course.

During the early group sessions, participants learn to prepare distraction-free teaching environments and to master the scripts and procedures of the instructional programs they are to follow (see section on program materials later). They also practise behaviour management techniques, including prompting and reinforcing, how to monitor progress and how to generalise program content. The teaching sessions usually involve two psychologists as tutors. The methods used include demonstration, role-playing, corrective feedback and rehearsal. In each session, all parents report back in detail on teaching sessions they have carried out the previous week.

Regular supervision and tutorial sessions with individual families begin in Week Two and parallel the group meetings. These sessions are conducted at home, or in the clinic, with one of the tutors, the parent(s), and their child in attendance. The tutor observes the parent teaching the child, provides reinforcement and corrective feedback, and demonstrates good practice if necessary. Video feedback of these lessons is used extensively. At the end of an individual session, the parents are helped to solve any problems arising and specific goals are set to improve their instructional or managerial techniques. Tutors also complete an Instruction Skills Checklist (see Figure 2).

Figure 1: The Timetable of a PEPS Training Course

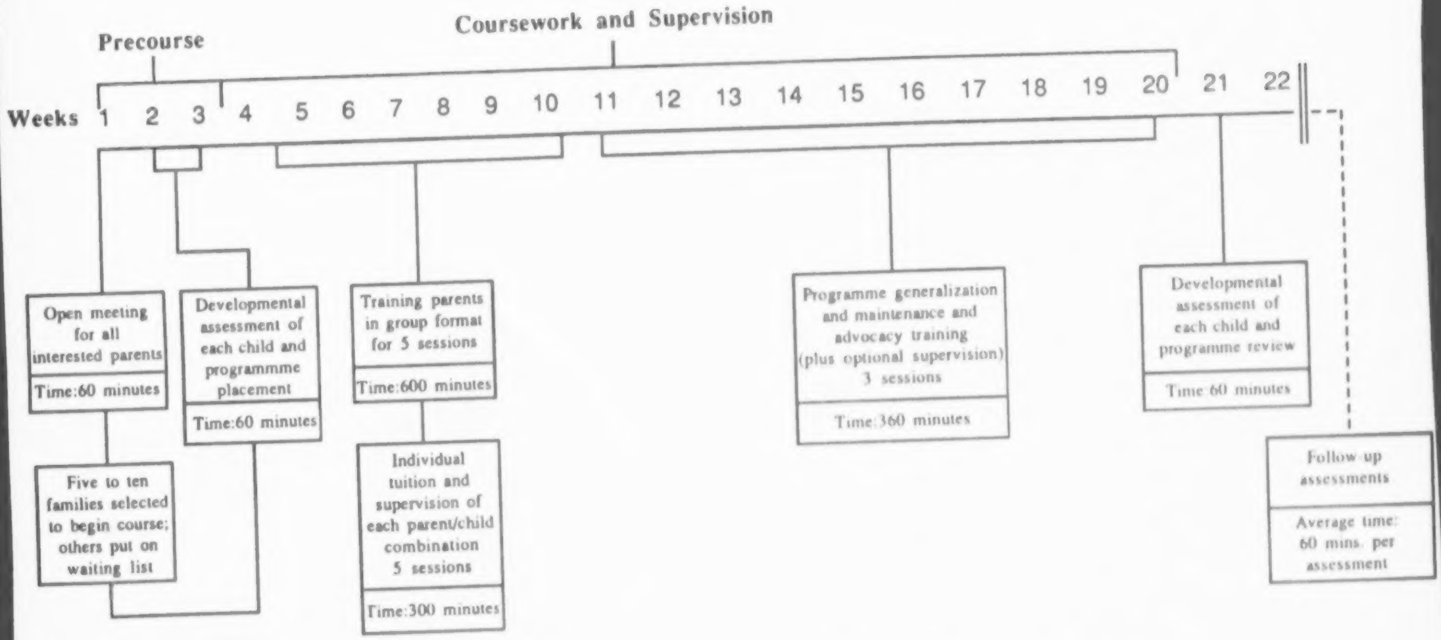
Coursework and Supervision
Precourse
Weeks
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22
Open meeting for all interested parents
Time:60 minutes
Five to ten families selected to begin course; others put on waiting list
Developmental assessment of each child and programmme placement
Time:60 minutes
Training parents in group format for 5 sessions
Time:600 minutes
Individual tuition and supervision of each parent/child combination 5 sessions
Time:300 minutes
Programme generalization and maintenance and advocacy training (plus optional supervision) 3 sessions
Time:360 minutes
Developmental assessment of each child and programme review
Time:60 minutes
Follow-up assessments
Average time: 60 mins. per assessment

Figure 2: INSTRUCTION SKILLS CHECKLIST

1. Observe session
2. Provide feedback & reinforcement
3. Demonstrate
4. Complete checklist
5. Plan future sessions

Child: ____________________

Instructor: ____________________ Program/lesson ____________________

Supervisor: ____________________ Date ____________________

Time Start: ____________________ Time Finish: ____________________

Instructor's Score: A ______ (8) B ______ (6) C ______ (7) D ______ (4)

E ______ (5) TOTAL ______ (30)

CHECKLIST (KEY: YES — Achieved NO — Not achieved N/A — No opportunity or not applicable)

A. Before Program **Rating** **Comments**

1. Setting
    - a. child alert and active
    - b. no distractions
    - c. appropriate seating/position
    - d. program materials set up
    - e. reinforcers arranged

2. Beginning Session
    - a. Introduce program positively
    - b. child's attention gained
    - c. correct program section used

B. Program Delivery Skills

1. Verbal/Non-verbal content
    - a. correct content spoken
    - b. eye contact/attention gained before giving instructions
    - c. clear and enthusiastic delivery
2. Pacing and Timing
    - a. brisk pace with short gaps between trials/ instructions
    - b. just enough time for child to respond before prompting
    - c. child mastery criteria reached before progressing to next major step in task sequence or logical reason given for moving on and/or returning later

C. Prompting and Reinforcement

1. Prompts
    - a. appropriate correction applied to errors
    - b. verbal/physical prompts given at correct level of intensity
    - c. prompts faded appropriately

Rating **Comments**

2. Reinforcement
   - a. reinforcement (verbal/ tangible) given at appropriate frequency and ratio
   - b. varied and enthusiastic reinforcement given
   - c. appropriate level/type of reinforcer given
   - d. period after program reinforcing

D. Disruptive Behaviour Management

- a. minor inappropriate behaviour ignored or incompatible program response prompted
- b. slashed back to easier task if minor disruption or noncompliance
- c. major disruption management strategies applied appropriately (eg time out)
- d. program continued to completion after minor or major disruption

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E. After Program

1. Recording
   - a. program progress summary completed
   - b. appropriate instructional modifications planned for next session (if any)

2. Generalisation
   - a. opportunities or prompts for child's program skills preplanned in non-program setting(s)
   - b. reinforcers for child's generalised behaviour arranged
   - c. incidental teaching strategies planned

NOTES

1. Goals for next session

2. Problems? Self-Reinforcement? Likely Maintenance? Social Supports? Stressors?

Individual supervision sessions continue until parents reach the mastery criteria of 90% total correct on the Instruction Skills Checklist. Once parents reach mastery, the sessions are faded out to increase their confidence in delivering programs independently. Postal and telephone contracts are also encouraged to bridge the gap between direct supervision and independence. Throughout the course (and after), parents are asked to keep records of the time they spend on instruction and the lessons completed.

Following the intensive group and individual training sessions, parents continue to meet as a group for a further three sessions on a fortnightly and then a monthly basis. These sessions focus on program problem-solving, generalisation and maintenance of parent teaching skills, working effectively with professionals (e.g. at case conferences), the structure and practice of local services for disabled children, the law and their rights, and how to gain access to the least restrictive environments for their children. In general, as the parents become more competent instructors, the emphasis shifts from instructional concerns to child advocacy issues. Similarly, course tutors move from their role as instructors, where communication is relatively didactic and unidirectional, to collaborative consultants where communication is as equals and expertise is shared.

A post-course assessment of each child is completed after the final group meeting. This provides data on the child's progress and indicates whether major program changes are indicated or not. Usually a post-course group meeting is held when parents are asked to evaluate the course as a whole and provide feedback to course tutors. Finally, parents are encouraged to join a parent support group that is run by previous participants of the training course. The group provides an important source of social support and rents out materials to parents who need to move on to new programs as their children progress.

After completion of the course, parents are expected to continue to teach their children using the recommended program materials and to keep records of their involvement. Although ad hoc contact with course tutors can be initiated if they wish, it is expected that they will teach as independently as possible of our help. Many families have been followed up on a five-monthly basis to check on their child's progress and their own instructional skills. Some provide up to five years of follow-up data.

4. Program Materials

As the maintenance of parental efforts following training has often been short-lived, we decided to use pre-designed and, where possible, **scripted** programs for instruction. We believed that these would relieve parents of the time-consuming and inappropriate demands that have been made on them to create their own lessons from general principles, and would be congruent with the aim of helping parents become maximally independent of expert help for programming delivery.

The instructional programs used to date have been Distar Language I and II (Engelmann & Osborne, 1976), Task Analysed Language for Kids (T.A.L.K) (Formentin, 1977), the RE-ED Early Language Programme (Leach & Leach, 1985), and a Prescriptive Behavioural Checklist for the Severely and Profoundly Retarded (Popovich, 1977). Older children have been placed on Distar Reading I (Engelmann & Bruner, 1975), Spelling Mastery (Dixon, Engelmann & Meier, 1980), and Distar Arithmetic (Engelmann & Carnine, 1975). These programs vary in their range and complexity and in the degree to which they are scripted for instruction. However, they share a basic behavioural framework and a common core of management and delivery skills. Most importantly, put end to end, they provide a developmental pathway from 10 months through to the primary school years.

(a) DISTAR Language

The Distar programs are the best researched and most detailed of those used in the course (e.g. Lockery & Maggs, 1982). They combine pre-tested, scripted lessons with specified teaching procedures based on a common logic for the design and sequencing of teaching examples which aim for generalised rule and concept learning. The Distar language program teaches comprehension and production skills. Its content includes teaching object names, classes, properties, relational terms, the use of correct descriptive statements, and the application of logical thought processes like conditionality, causality, deduction and inference.

Children are placed on the Distar Language program when they have mastered the relevant pre-skills and, as a minimum, are able to produce intelligible, four-word utterances.

(b) T.A.L.K.

The Task Analysed Language for Kids program is based on the intervention strategies for language delayed children described by Bricker, Ruder and Vincent (1976). TALK does not have the curriculum structure nor the logical sequencing of Distar and is far less scripted. However, it does set out a series of discrete, loosely-related objectives, describes necessary materials and provides guidelines for teaching procedures. The program begins with a brief section on attention and following directions before progressing quickly to physical and sound imitation, word-action associations, word production, agent-object-action relations and more complex three-word sentence constructions.

Children have been placed on the TALK program if they can comprehend and follow simple instructions and have begun to produce some recognisable sounds or word substitutes. Unfortunately, no formal evaluation of TALK in its present form has been published and this project provides the first data on its usage with a sample of disabled children.

(c) Popovich

The Popovich Behavioural Checklists provide a series of developmentally sequenced, task-analysed objectives for teaching pre-language and early language and cognitive skills. (In addition, there are motor and self-help skills which are not used in the project.) The program moves from one discrete developmental activity to another from a point approximately equivalent to a one-year-old level of development. The steps between objectives vary considerably in steepness. Brief descriptions of tasks, materials and procedures are given but only general instructions for teaching are provided. These are not in a scripted lesson format. In the Language domain, the program aims to teach attention, sound and object discrimination, following simple commands, and the identification and labelling of objects.

A small group of very young and severely handicapped children with developmental skills up to 15 months have been placed on the Popovich program early in the project. As with TALK, however, we have not been able to find other evaluations of the Popovich program in the literature.

(d) RE-ED

In the first few years of using the TALK and Popovich programs, our experience suggested that there were significant problems with them when used by parents. The Popovich program in particular had many gaps in its sequence of skills and, though targeted at the severely and profoundly handicapped group, lacked the fine sequencing and direction to enable parents to teach independently of professional guidance. TALK had similar structural problems although to a lesser extent. Also, many of the children in our groups have shown non-compliant behaviours either initially or after two or three weeks of instruction. As it is essential for the maintenance of programs that these non-compliant behaviours are properly managed and reduced to allow teaching to proceed, we found that neither the Popovich nor the TALK program had sufficient content to teach initial compliance to requests when this was required.

In view of these difficulties, we wrote a new direct instruction program to replace TALK and Popovich for children in the ten month to three and a half years developmental age group. This has been provisionally called the RE-ED Early Language Programme (Leach & Leach, 1985).

The RE-ED program is a finely stepped, integrated teaching program which is composed of fully scripted lessons and generalisation activities. The first volume emphasises generalised imitation and compliance training with some object discrimination. Later, the child moves to object and picture identification, imitation of sounds, imitation and recognition of words and basic concepts, and ends with the production of three and four word sentences, thus keying into the Distar Language program. Although oral language is targeted, the content has been adapted successfully for non-verbal children and those needing a total communication system of signing and speech. Some preliminary results of its use on the PEPS course are presented here.

5. Course Participants

Data will be presented on the 61 families who have used the four language programs: Distar, T.A.L.K., RE-ED and Popovich. These will be grouped for description according to the program used.

(a) The Parents

The socio-economic status of each family has been assessed on a 0-6 scale according to the occupation of the highest income earner in the family (Linacre, Karmel, McBurney & McEwin, 1980). The overall mean rating is 3.7, which indicates a 'skilled working class' to 'lower middle class' bias. There are no statistically significant differences between groups. In all but three cases, the child's mother has chosen to be the primary instructor. However, the majority (60%) of parents have attended the course with spouses, relatives, or volunteers (see Table 2). There has been a strong tendency for parents to attend together or with others to a greater extent when their child has been young (below 3 years) or more handicapped (non-speaking). This tendency may be due to differences in (realistic) parent expectations regarding the difficulty of teaching their children or in their own (real) needs for greater social support whilst doing so. The maintenance of initial attendance during the course has been very high with a mean of 97% attendance at all course sessions. Only one family has dropped out during the course and is not included in the data.

(b) The Children

The pre-course characteristics of the children are presented in Table 2. These figures are taken from the results of the Developmental Profile II Scales. As would be expected, the Distar group has been older on average (x 5.1 yrs) than the other groups and has tended to have higher IQ equivalents (x 80.2), communication ages (x 3.7 yrs) and physical ages (x 3.6 yrs). The TALK and RE-ED groups have averaged approximately 3.7 years in chronological age with much lower communication and physical quotients indicating greater developmental delays. The RE-ED group has been the most delayed in language/communication (communication quotient x 27.8) and the Popovich group the youngest on average (x 2.6 yrs).

TABLE 1:

MEAN BEGINNING COURSE DEVELOPMENTAL CHARACTERISTICS OF CHILDREN BY PROGRAM

PROGRAM	CA (in months)	IQ Equivalent	COMMUNICATION AGE (in months) (Developmental Profile II)	COMMUNICATION QUOTIENT (CA/Com. Age)	PHYSICAL AGE (in months) Profile II)	PHYSICAL QUOTIENT (CA/Physical Age)
DISTAR **(N = 13)**	60.6 (44-82)*	80.2 (60.9-89.4)	43.4 (30-58)	71.6 (52.7-80.8)	46.9 (22-72)	77.4 (44-96.2)
T.A.L.K. **(N = 21)**	44.6 (22-69)	49.1 (33.9-66.7)	19.1 (8-40)	42.9 (19.0-68.9)	23.7 (14-34)	53.1 (38.0-81.8)
RE-ED **(N = 22)**	43.2 (17-66)	40.4 (12.7-72.2)	12.0 (2-40)	27.8 (.06-60.6)	18.6 (2-42)	43.1 (.06-79.2)
POPOVICH **(N = 6)**	31.6 (22-49)	37.9 (17.4-48.9)	11.6 (4-26)	36.7 (19.5-53.1)	14.8 (2-30)	46.8 (.08-75.0)
MEAN	45.0	51.9	21.5	44.8	26.0	55.1

* = (Range)

TABLE 2:

PARENT TEACHING SKILLS AT THE BEGINNING AND END OF THE TRAINING COURSE, WITH NUMBER OF WEEKS TO MASTER THE PROGRAM AND COURSE ATTENDANCE.

PROGRAM	BEGINNING TEACHING SKILLS (5)	END OF COURSE TEACHING SKILLS	NO. WEEKS TO MASTERY	ATTENDANCE (%)	ALONE (%)	WITH OTHERS (%)
DISTAR **(N = 13)**	64.7 (20-85) *	87.9 (80-100)	3.7 (3-5)	98	69	31
T.A.L.K. **(N = 20)**	51.4 (10-70)	74.8 (60-88)	4.5 (4-5)	97	48	52
RE-ED **(N = 22)**	41.4 (10-80)	79.1 (60-100)	3.9 (3-5)	100	23	77
POPOVICH **(N = 6)**	42.8 (36-59)	66.0 (60-70)	5.2 (4-6)	93	0	100
MEAN	50.1	77.0	4.3	97	35	65

* = (Range)

The developmental delays of the majority of children have been suspected or known to be associated with physiological etiologies such as Down syndrome, autism, cerebral palsy, spina bifida, tuberous sclerosis, viral infections or birth traumas.

COURSE EVALUATION

Information has been gathered over a five-year period on two aspects of the course's effectiveness: the impact on the parents' instructional behaviour and the effects of that instruction on their children's development. The data have been used to ascertain whether the course has improved parents' instructional skills, whether parent instruction time is maintained after the course, and whether the children make gains in their rate of development both during the course and at long-term follow-up. Inevitably, the latter question has incorporated that concerning the effectiveness of the particular instructional programs used in addition to the efficacy of the parent training itself.

1. Effects on Parent Instructional Skills

Tutors rate parents on the Instruction Skills Checklist during each individual supervisory session and at the end of the course. A summary of the beginning and end of course skills with the number of weeks it has taken for parents to reach instructional mastery (criterion: 90% of listed skills) is given in Table 2.

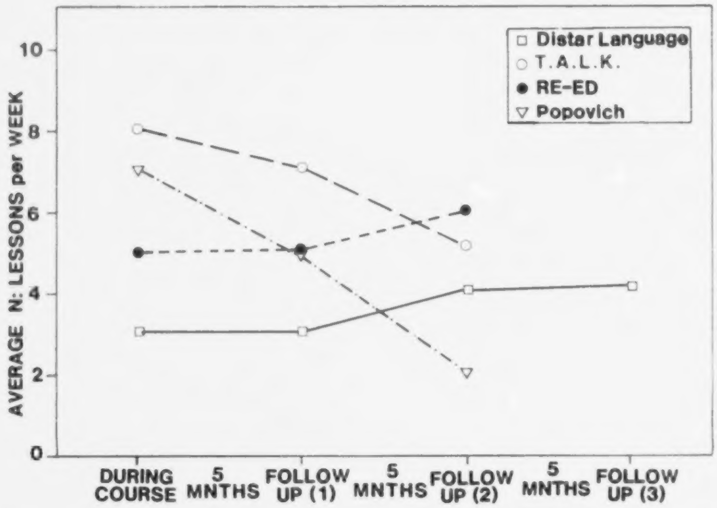
All parents in the language group have increased their instruction skills during the course from an initial group mean of 50.3% to a mean of 77%. The average time to reach mastery has been a surprisingly short 4.3 weeks. The Distar group has had more initial skills than the other groups probably because the children have been more compliant and easier to teach than in the other groups. Significantly, they also have taken less time to reach the mastery criterion than the others and have maintained their skills at a higher level throughout the course (88% at completion). The Popovich group has taken the longest time to reach mastery (5.2 weeks), and has been less likely to maintain their skills (66%) at completion. This may be due to the slightly younger children in the group, although, as will be seen later, it is probably indicative of the lack of script and task integration in the program. The TALK and RE-ED groups have performed between these two extremes with the RE-ED group exhibiting a little more maintenance of skills than the TALK group during the course.

The mean time spent by parents on instructing their children, the length of formal lessons, and the frequency of the lessons has been taken from their own records which they are asked to keep during the course and afterwards. The total hours per family per week taught by the Distar group has averaged 2.1 hours (Range 1.3 to 3.5) during the course, with an average lesson length of 33.2 minutes. These figures have maintained well over a lengthy period following the course. For example, at fifteen months follow-up, parents have reported an average of 3.7 hours (Range 2.0 to 4.4) of instruction, with lessons averaging 46.7 minutes. The TALK group has totalled an average of 2.2 hours per family per week (Range 0.35 to 4.0), with lessons averaging 15.7 minutes (Range 7 to 24). This group dropped slightly to 1.7 hours total time per week (Range 0.4 to 4.0) on average at ten months follow-up with lessons averaging 17.6 minutes (Range 10.0 to 24.2). The RE-ED group has totalled 1.6 hours per family per week during the course (Range 0.34 to 2.9), with lesson length averaging 12.3 minutes (Range 5.0 to 23.6). The group has maintained well at follow-up such that, after ten months it averages 1.7 hours per family per week (Range 6.3 to 25.0). The Popovich group averaged 1.4 hours per family per week (Range 0.3 to 2.7) during the course with lessons averaging at 11.3 minutes (Range 3.0 to 22.0). This effort was found to decline sharply at ten months follow-up, however, with the group averaging only 0.7 hours per week (Range 0.3 to 1.4), although the lesson length did increase to 17.9 minutes (Range 12.0 to 20.4). As was stated earlier, an interest of these figures has been the accumulated time spent by parents on delivering programs which present developmentally relevant tasks to children with a high degree of success. Such academic learning time has been shown by numerous studies to correlate highly with the basic achievements of children in regular schools and there is no good reason why it should not predict achievement in younger and disabled children.

We are analysing our data to examine the relationship between time spent on teaching and progress made by children with similar skills but we have yet to complete it. Thus, the relationship between total time and progress must, as yet, remain speculative with this population. However, should it prove significant, the enormous amount of academic learning time accumulated by these preschool children in all groups (e.g. 225.6 hours per family by the Distar group over 19 months), is certainly far greater than they would ever receive from professional services in the normal course of events, and should increase their learning rates beyond previous expectations.

Equally important has been the use of the time measures to ascertain whether or not parents have maintained their efforts on completion of the course. The total time spent on programs is not a good index of this effort as lesson lengths vary between programs and, of course, reflect differences in children's ages and degrees of disability as much as effort per se. We have found that a better measure of effort is the frequency of lessons per week. These data are presented in Figure 3.

FIGURE 3: MEAN NUMBER OF LESSONS PER FAMILY PER WEEK ACCORDING TO PROGRAM GROUP



It was partly because of the lesson frequency data that we decided to write the RE-ED program. As can be seen, the Distar group maintained their efforts extremely well whereas the TALK and Popovich groups began to fall away after the course. Yet, since the introduction of the RE-ED program, the families of the young and more handicapped children have managed to maintain their efforts without help in a similar way to the Distar group. This suggests that the program variable is more important as a predictor of persistence than the characteristics of the children as we first thought. We need to make further follow-ups to see whether or not the trend for the RE-ED group continues over the longer term.

In summary, the time data show that there has been as much parent instructional effort after the course as during it (particularly by Distar and RE-ED groups) and that only the Popovich group has reduced its total instructional time significantly on completion of the course. This is a promising finding in view of the rapid decline in parent effort that is normally reported during post-training periods. (e.g. Rees, 1982).

2. Effects on Children's Development

The target areas of the parent-delivered programs have been language/communication skills and, to a lesser extent, academic/cognitive skills. Having shown that the parents were continuing to teach, it was hypothesized that, if the programs were being effective, their children's development in these areas would accelerate to a greater extent than in other areas, such as physical skills, which have not been targeted. It was also hypothesized that, of those parents who continued to teach after the course, their children would at least maintain any gains made during the course and might well continue to make progress at an accelerative rate.

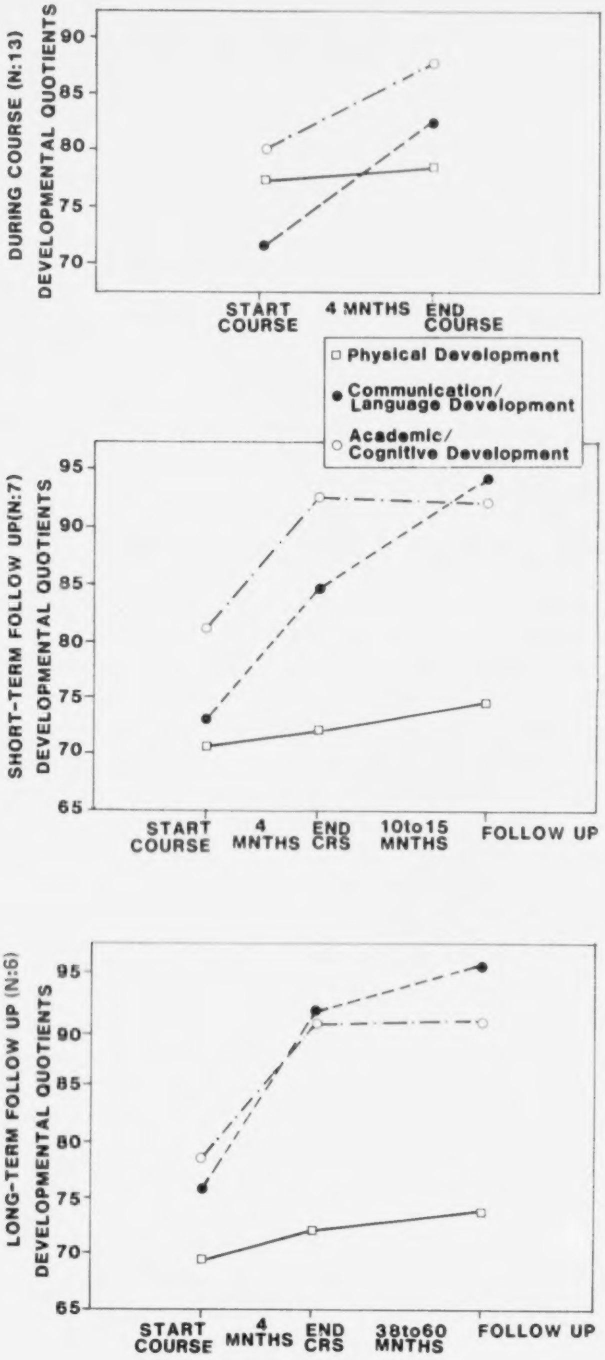
Figure 4 summarises the developmental data in the areas of communication/language skills, academic/cognitive skills and gross and fine physical skills for the Distar group children. The measures were taken from the Developmental Profile II test. The scores are expressed as mean quotients which have been calculated by dividing the children's developmental ages in the three areas by their chronological age at the time of testing. This allows comparison with a hypothetical normal peer group (mean rate of normal development = 100) and also shows whether the rate of development is accelerating (quotients increasing), remaining constant (quotients stable) or decelerating (quotients decreasing).

On the whole, the Distar group has shown a strong acceleration of progress over the comparatively short period of the course with the average increase in quotients for communication/language skills being 11.3 points. There has also been a significant increase in the rate of acquisition of academic/cognitive skills with quotients rising on average 7.9 points. The likelihood of these gains being due to non-program or course factors is somewhat remote when the points are compared to the changes in the rate of acquisition of physical skills by the same children over the same period. These have remained quite stable.

More importantly, in the group of parents we have followed up so far, there have been good indications that their children's development has continued to accelerate in the communication/language area even as much as 3 to 5 years after the end of the course. Indeed, average quotient gains of 19.8 points have been made by these groups from the start of the course to long-term follow-up. Similarly, the rate of gain by the children in the academic/cognitive area has maintained at the higher level achieved during the course with only a very slight but non-significant deceleration at long-term follow-up. The children's rate of growth in physical skills, however, has changed very little with only a slight acceleration noted over the long-term.

The TALK group has followed a similar pattern to the Distar group with acceleration in the

FIGURE 4: MEAN GAINS IN DEVELOPMENT QUOTIENTS DURING THE COURSE AND AT FOLLOW-UP BY THE DISTAR GROUP



acquisition of communication/language skills and academic/cognitive skills during the course and at long-term follow-up 2 to 5 years later (see Figure 5). Again, their physical development has remained fairly constant over the same period. The only difference between the Distar and TALK groups has been in the rate of acceleration where the TALK group has increased slightly less than the Distar group, with gains of 6.7 quotient points on average in communication/language skills during the course and 19.1 quotient points at long-term follow-up. However, there remains the problem of a slowing down in effort by the parents in this group as has been discussed earlier.

The Popovich group has been the least successful. The children have shown little acceleration in target skills during the course (x 0.6) and, although their physical skills actually decelerated during this time, their long-term maintenance has also been unsatisfactory (x 3.1) (see Figure 6). When taken in conjunction with the slowing down in parental effort, it became clear some time ago that either the course in its present form was less effective for these parents, or the Popovich program itself was problematic, or that both factors were operative. Whatever the reasons, although the sample size was small, we felt the data were strong enough to decide to replace Popovich with the RE-ED program for the younger or more disabled children rather than radically modify the training course.

To date, twenty-two families have completed the training course using the RE-ED program and eight families have provided data on its effects up to 2½ years after course completion. Despite having the lowest quotients for communication and language skills of all the children in our groups, the results have been most encouraging (see Figure 7). The children have shown accelerated progress in target skills during the course relative to gains in physical skills, with average gains in communication/language quotients of 8.2 points. More importantly, this acceleration has continued so far at long-term follow-up where average gains of 23.5 points have been recorded. These have been remarkably similar to the kinds of gains made by the Distar group and have, on the whole, fully supported our decision to persevere with the original course format for the younger and more difficult-to-teach children.

3. Effects on Parent Advocacy Skills

The effects of the course on parent advocacy skills cannot be assessed objectively at this stage as data is still being analysed. However, we have some evidence to suggest that the course has had an impact. For example, 64% of parents with appropriately-aged children have managed to enrol them in integrated preschools or regular schools. This figure seems higher than the typical local enrolment rate of similarly disabled children. Also, 89% of all parents have reported that the course gave them information and encouragement to take a more active and assertive role when working with professional service providers than the one they had taken prior to the course.

A more tangible outcome has been the establishment of an independent, parent-run, self-help and support group (Parents as Educational Partners) which was formed five years ago by members of the first courses we ran and which emerged during the advocacy sessions. This group has provided new course participants with information and personal support to help them maintain their teaching efforts and reach the goals they set for their children. It has also raised money to buy new materials for families to rent at low cost which enables them to move on to new direct instruction programs as their children progress. During 1985, the group secured Commonwealth funding to employ a coordinator and three instructional aides. The staff were employed to support parents conducting programs with their children at

FIGURE 5: MEAN GAINS IN DEVELOPMENTAL QUOTIENTS DURING THE COURSE AND AT FOLLOW-UP BY THE T.A.L.K. GROUP

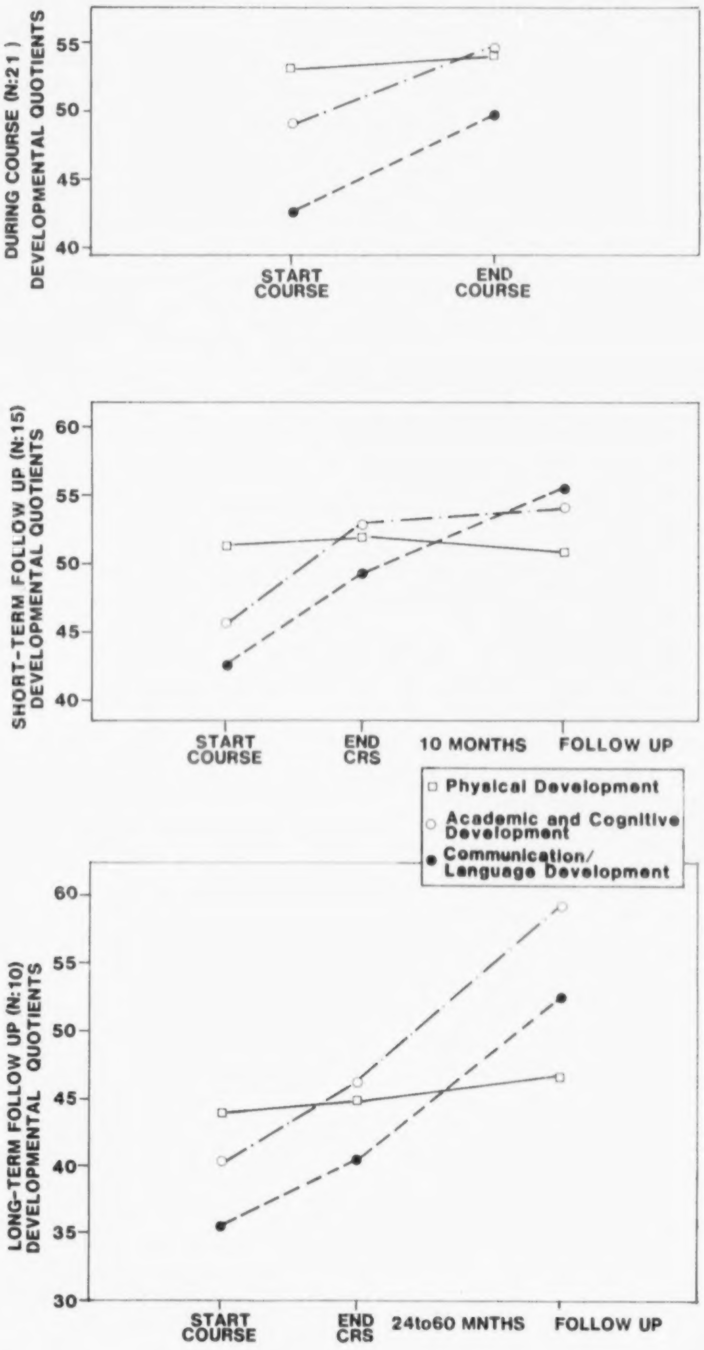


FIGURE 6: MEAN GAINS IN DEVELOPMENTAL QUOTIENTS DURING THE COURSE AND AT FOLLOW-UP BY THE POPOVICH GROUP

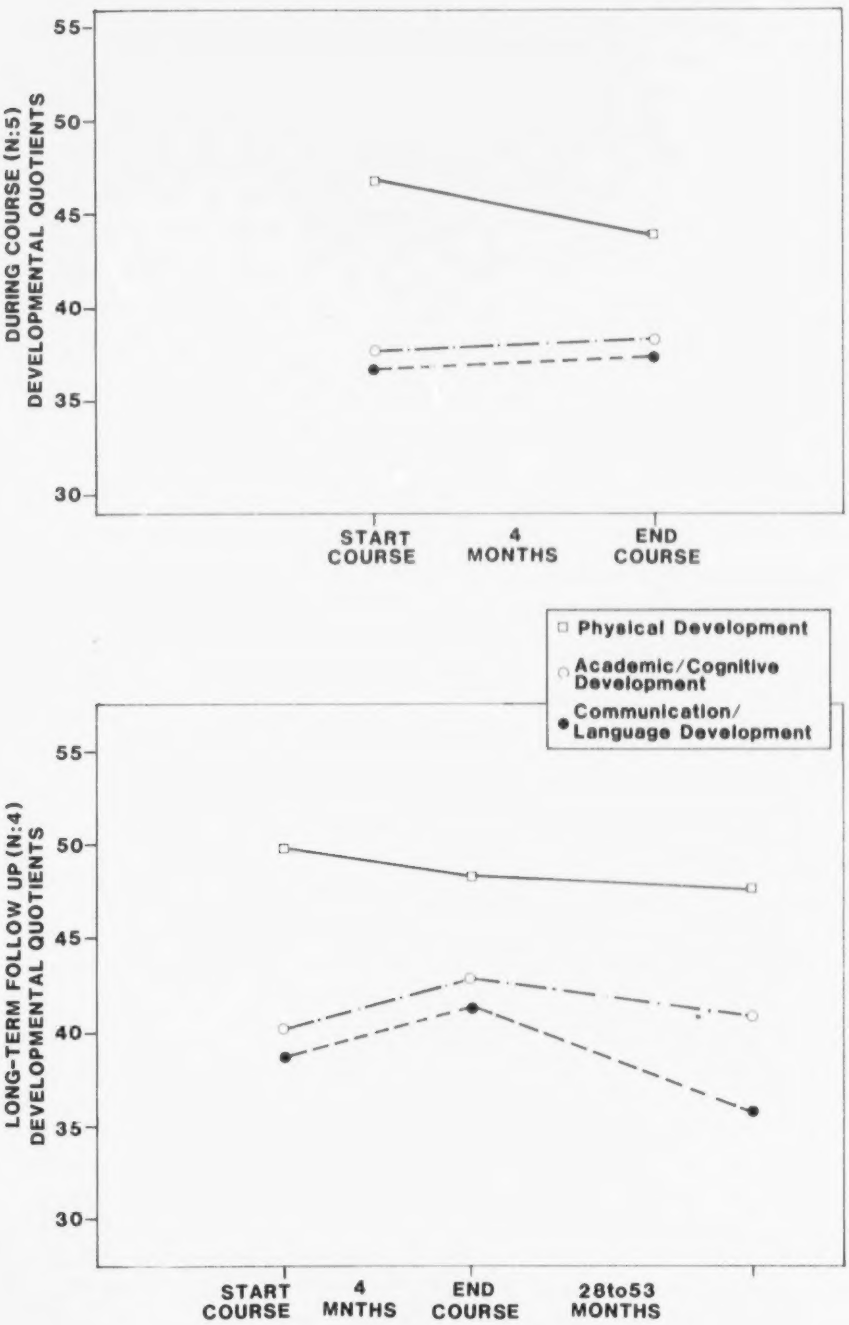
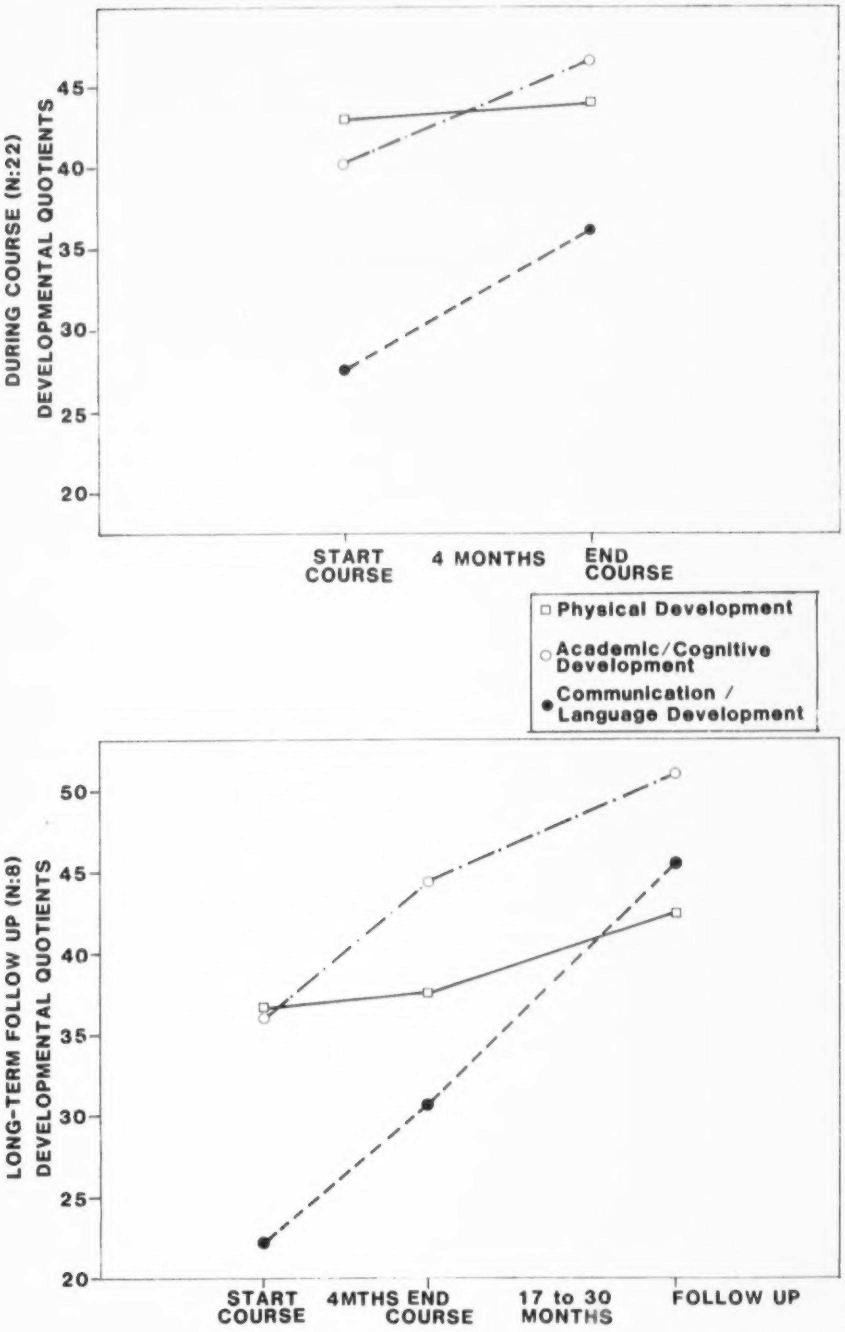


FIGURE 7: MEAN GAINS IN DEVELOPMENTAL QUOTIENTS DURING THE COURSE AND AT FOLLOW-UP BY THE RE-ED GROUP



home or at school and to help integrate their children in the least restrictive educational environments that could be arranged. Unfortunately, the CES grant was for one year only and this interesting development was prematurely curtailed.

It is likely that the independently conceived and organised PEPS support group has made a significant contribution to the success of the course. Although only half the parents have joined the group, the existence of a body of like-minded and experienced people which others have been able to contact either formally or informally, and which has provided back-up material support when needed, has been welcomed by parents who would otherwise have had to 'go it alone'. Indeed, we have some data which suggest that formal membership of PEPS is a predictor of long-term instructional effort. We hope to report more on the advocacy components of the course and their effects in the future.

4. Course Cost-Effectiveness

The PEPS course has been wholly supported by the direct contributions of participating parents on a nominal fee for service basis. From the point of view of time, however, assuming that two tutors are needed for group meetings and one tutor for individual sessions, the average professional contact time per family during the course has been 11.6 hours. Follow-up assessments have required a further 1½ hours each. The ratio of professional time as tutors to parent teaching time with children during the course has been very encouraging ranging from 1:2 for the Distar group, 1:2 for TALK, 1:1.7 for RE-ED, and 1:1.4 for Popovich. After 10 months this ratio increased to a much higher level: 1:12.3 for the Distar group, 1:9 for TALK, 1:7 for RE-ED and 1:4.7 for Popovich and is still increasing. The ratio of professional time to children gains has been even more encouraging. Over all groups, for every 1 hour spent by the tutors with a family, their child has gained an average of 2.2 communication quotient points over the course and 4.8 communication quotient points at 10 to 15 months follow-up.

It would have been most useful if other parent courses or services for disabled children had reported similar indices of their cost-effectiveness so that we could have compared and judged the significance of these figures against valid yardsticks. As it is, they are presented for others to use to compare and judge in the future.

CONCLUSIONS

The evaluation of the PEPS course is continuing. What began as a small demonstration project has now become a major research program. We have begun a much needed comparison study of its effectiveness as measured against other types of training and a waiting list control group. We are looking further at the predictions of parental long-term instructional effort, its effects on family behaviour and adjustment, and the influence of its advocacy components. We are re-working existing time and outcome data using more sophisticated statistical analyses as the groups increase in size. Until this work is completed, there will be a number of unanswered questions about the efficacy of the approach to involving parents and providing services to disabled children that we have adopted.

At present, the conclusions we can draw are necessarily cautious. On the whole, however, it may be said that the project has demonstrated that committed parents can be taught to be highly effective, independent instructors of communication/language and academic/

cognitive skills with their own mild to severely disabled children in a cost-efficient, brief training course. Although speculative, the following seem to be the significant components of the course that differentiate it from the typical behaviour training model:

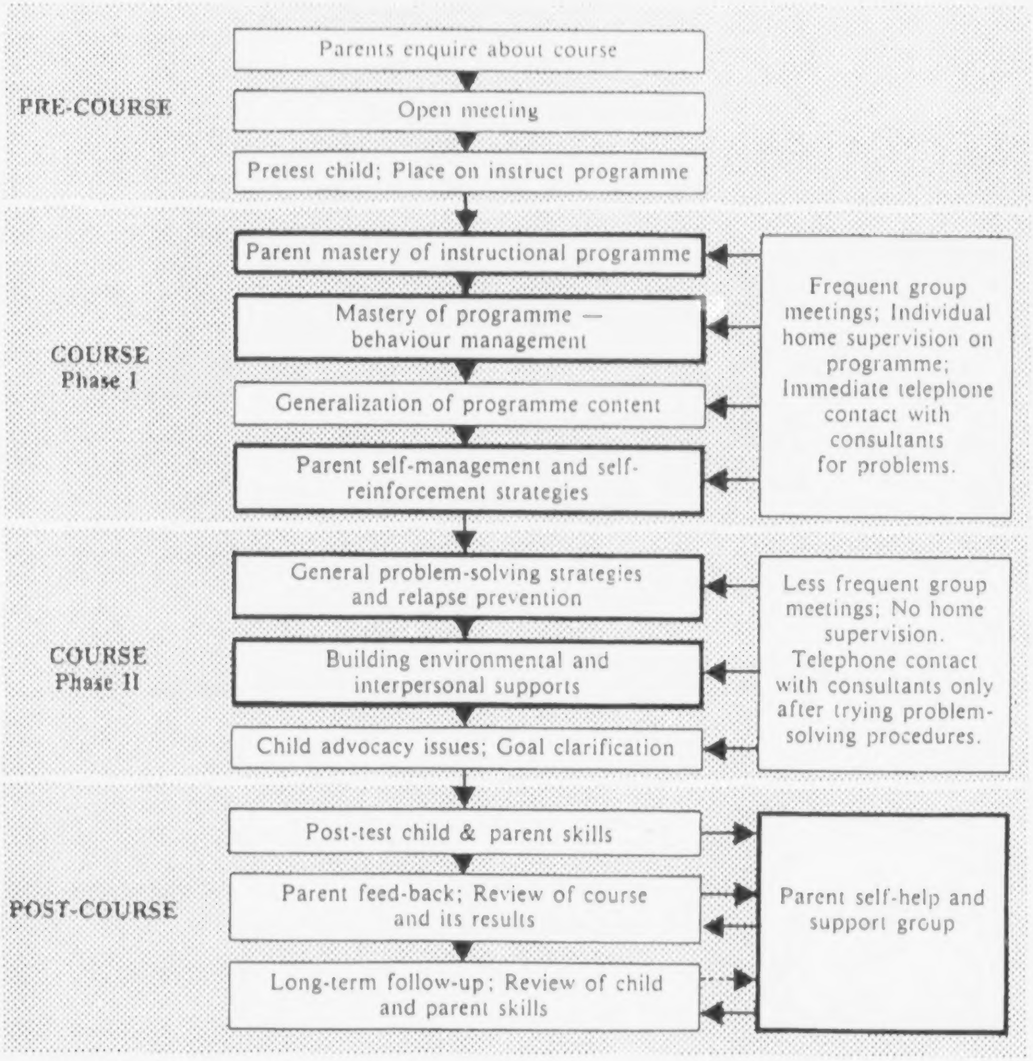
1. it uses scripted programs which free the parent from demanding lesson design and curriculum planning issues and enables them to concentrate on the managerial aspects of instruction;
2. it focuses initially on specific, program-related delivery skills which are taught to mastery criteria and which are then generalised to other settings, programs and behaviours (including incidental teaching);
3. it teaches parent self-management, self-reinforcement, and program problem-solving strategies and encourages parents to build environmental and social supports to help maintain their instructional behaviour;
4. it teaches child advocacy skills to aid goal clarification and future planning and to develop feelings of personal control and self-worth, and
5. it teaches independence by gradual shifts in tutor roles from didactic-expert to collaborative-consultant and by increasing time intervals between supervision and group sessions.

These features have been incorporated in a basic model for parent training with disabled children which is described in Figure 8.

Finally, we feel that an important ingredient of the PEPS course that could well be essential to its effectiveness is the creation of an overriding tenor which can best be described as parent 'empowerment' (Dunst & Trivette, 1987). In other words, we try to promote a sense of personal control over their children's problems by enabling them to refine and use their existing skills as much as possible in their interactions with them, by providing them with access to effective programs, by teaching them instrumental behaviours to interact effectively with professionals to procure services and resources and by developing their decision-making and problem-solving skills as they relate to their children. This infers an attitude towards parents which starts with the assumption that they are all potentially competent to manage their children and ends with the belief that they are experts who act as the coordinators of the programs, resources and services their children need.

Unfortunately, this attitude is often missing in the approach to parent involvement by professional service providers. In many instances, services act in ways that usurp the active involvement of parents by preventing them from learning new competencies, creating feelings of indebtedness, inferiority, helplessness and dependency and failing to provide what they require. Perhaps it is because of this underlying philosophy of parent training that we have never experienced nor have had reported the kinds of emotional or physical overloads that some have suggested may result from this kind of parent involvement (e.g. Rodger, 1986). Rather, our experience has been that the great majority of families have benefited emotionally and socially from their more purposeful and empowered position. Indeed, it seems to have had an energy-releasing effect rather than an innervating one. Clearly, more objective data is required to throw light on this question, but the long-term successful involvement of the families in instruction does point to the reinforcing nature of the interchanges with their children rather than a punitive one. Negative effects on families seem to us to have been more firmly related to the frustration and anger they feel towards the lack of adequate resources, the usurping practices they are subjected to, and the lack of feelings of control over their children's excessive behaviours and deficits they face day by day.

FIGURE 8: THE PEPS PARENT TRAINING MODEL


PRE-COURSE
Parents enquire about course
Open meeting
Pretest child; Place on instruct programme
COURSE Phase I
Parent mastery of instructional programme
Mastery of programme — behaviour management
Generalization of programme content
Parent self-management and self-reinforcement strategies
Frequent group meetings; Individual home supervision on programme; Immediate telephone contact with consultants for problems.
COURSE Phase II
General problem-solving strategies and relapse prevention
Building environmental and interpersonal supports
Child advocacy issues; Goal clarification
Less frequent group meetings; No home supervision. Telephone contact with consultants only after trying problem-solving procedures.
POST-COURSE
Post-test child & parent skills
Parent feed-back; Review of course and its results
Long-term follow-up; Review of child and parent skills
Parent self-help and support group

On the other hand, we can only talk about parents who have sought out the kind of intensive involvement we have described. We would agree wholeheartedly with the call for the provision of a range of parent involvement options and greater service flexibility (Turnbull & Turnbull, 1982). What we would stress, however, is that this should not become an excuse for not providing this type of parent training for those who seek it. A large proportion of parents, children, and their families will needlessly miss out if it does.

FOOTNOTE: Hal Swerissen helped David Leach to establish the PEPS training model and initiated its evaluation during the years prior to his appointment in what was Lincoln Institute for Health Science in 1985. Since then, the courses and their evaluation have been conducted by David Leach in conjunction with Pauline Leach. Kate Smith and Leonie Vuorella have carried out some of the assessment and follow-up of children's progress.

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Chapter 28

INTEGRATION: QUALITY IN CARE AND EDUCATION FOR THE YOUNG DISABLED CHILD

Katherine S. Kenny

This paper aims to examine the criteria of quality for care and education programs for young disabled children in integrated early childhood settings. The conceptual and practical issues which influence quality programs will be discussed with particular reference to the Integration Programs operated throughout South Australia in early childhood centres.

The Integration Programs, developed to enable and support the integrated or normalised development of young children, have as their specific 'target' group individual children who are 'too delayed or disabled' to be able to participate fully or without direct assistance in community-based early childhood programs. Some of these children are extremely disabled and the handicapping conditions of others are exacerbated by severe lack of other available community resources, isolation and other factors.

Integration is more than 'being there'; it is a complex process based upon the recognition of human values and human rights. For greater insight into the Integration Programs an appraisal of the following aspects will be provided:

- the principles of integration
- the dimensions of integration
- the goals of integration

The dimensions of integration will be placed in relation to the indicators of quality in early childhood programs. The juxtaposition of these parameters of quality will lead to the emergence of guidelines for practical goalsetting and evaluation hallmarks of excellence in integration.

INTRODUCTION:

Ideology to Practice

In October 1985, I was fortunate enough to participate in a conference at which Brendt Nirje was the principal guest. Usually, normal Australian reserve or langour operates at such events to help us avoid 'over enthusiasm' and to remain 'objectively critical'. It was a mark of the man that Nirje, the acknowledged 'Father of Normalisation' overcame this incipient scepticism, and by the sheer strength of his humanity and energy drew his audience to reconsider their values and practical attitudes as they affect life practices, including work. In his discussion, Nirje emphasised that integration or 'normalisation' was an expression of ideology generated by societies. As such, the ideology of normalisation is both an instrument and measure of tolerance but one which often results in a choice 'between the impossible and the impracticable' (Nirje, 1985). If integration is to be pursued in a practicl way as a valuable social goal, a number of premises may have to be recognised. For integration truly to occur, experience of the normal conditions of life is essential.

To move from the ideological and ethical acceptance of the concept of integration to the practice of integration there are a number of practical considerations or criteria which must be met. These include:

- provision of opportunity for participation in real and functional environments,
- bringing the resources to where the children are,
- involving and supporting the families,
- learning to work together so that new knowledge can be created to benefit the disabled child and the community,
- co-ordination of services within the community,
- ensuring that service provision **works**,
- learning from the disabled. (Nirje, 1985)

Meeting these criteria by making demands on the public situation will ensure maximum self realisation. Nirje asserts that 'integration means that relationships between individuals are based on a recognition of each other's integrity and a recognition of shared basic values and rights' (Nirje, 1980). This should be kept in mind.

I. THE PRINCIPLE OF INTEGRATION/NORMALISATION

> 'The normalisation principle rests on the understanding of how the normal rhythms, sequences and patterns of life in any cultural circumstances relate to the development, maturity and life of the handicapped, and on the understanding of how these patterns apply as indicators for development of proper human services'. (Nirje, 1980)

The normalisation principle refers to combined areas of opportunity and social responsibility:

- **Opportunity** involves the experience of interactions, environments and learning opportunities within a real social context. Such reality or 'culturally normative' opportunities provide the opportunity for developing adaptive and functional 'behaviours, appearances, experiences and interpretations which are (in turn) as culturally normative as possible' (Wolfsenberger, 1972)
- **Responsibility** is itself two directional or reciprocal. On the one hand responsibility involves the macro responsibility of societies to ensure inclusiveness and equal opportunity to all members of the society. Where a person is disabled to ensure these rights will require both
  - conscious effort to enact appropriate attitudes and behaviours towards and involving the disabled individual, and
  - the adoption and adaptation of resources to enable the fulfilment of the goals of integration.

The response to societal responsibility and opportunity is the development of personal responsibility and independence.

II. THE DIMENSIONS OF INTEGRATION

For integration to be a holistic and pervasive process and experience, a range of areas needs to be included in any definition of integration. Nirje identifies six areas which elaborate the 'many interfaces between the individual and the social setting' and the relationships which occur within these areas.

1. **Physical Integration** — normalised location and sharing of the rhythms and securities derived from these settings.

2. **Functional Integration** — access to the activities which occurs within these settings.
3. **Social Integration** — involvement in 'interpersonal and impersonal social relationships'.
4. **Personal Integration** — opportunity for developing satisfactory personal interaction with significant others.
5. **Social Integration** — 'relates to the expressive functioning as a citizen including opportunities for growth, maturity and self-fulfilment through respected expressions of self-determination'.
6. **Organisational Integration** — responsive and flexible mainstream systems of administration, organisation and service which provide or enable the range of necessary specialist service to support the preceding five areas. (From Nirje, 1976)

III. GOALS OF INTEGRATION

For integration to be successful, that is, to be an enduring quality experience for the individual (and thus for society) two specific and explicit goals must be pursued. These major goals are:

1. **Stigma reduction or removal;** the amelioration, lessening or removal of 'the characteristics of a person which reduced his or her perceived value as a human being' (Galloway & Chandler, 1980). Reaching this goal requires work in addition to that undertaken with the *preventing* physical, behavioural and developmental needs of the disabled child. It also, and most importantly, involves the development of positive values and attitudes by (*in our relation to our programs*) the child about the self, and the development and activation of positive values and attitudes by others towards the disabled child. The goal remains an abstract concept if the child cannot interact with others in as normal a way as possible.

2. **Competency enhancement;** the support and encouragement of all aspects of development with the intention of assisting and guiding the child through the means of programmed and supported intervention toward optimum levels of development. This general goal will, in practice, lead to individualisation and the adoption of functional objectives. Each child's competency enhancement program will vary *one from the other*, both in terms of the immediate objectives, the techniques and methodologies involved, management of the environment and the deployment of staff to ensure positive interaction. Despite these variations, it is fundamental to the success of integration to ensure that the chosen aspects of program concentration at any time during its progress are functional: that is, the activities and skills, the developmental achievements intended, which the child experiences and develops are to be applied to the real coping world if they are to be considered valuable to that child. Fostering developmental competencies in constantly isolated or segregated situations suggests that opportunity of application will or may be limited. The possibility exists that skills or competencies thus developed become fragmented or reduced to their component parts having no real holistic meaning to the child. Competency enhancement involves more than simple task achievement: it implies the opportunity to apply those learned competencies as normally as possible.

3. **A subsidiary or tacit third goal (though by no means a lesser one) is to provide the family of the disabled child with support** — both developmental support for the child and practical opportunities for respite for (usually) the mother. Families with disabled children are greatly stressed and pressured. Because of the intensive time demands made on the

family, social isolation can result. Integration provides the opportunity for families to develop the necessary social networks of friendship and understanding in their own communities. Such social support and interaction are regarded as normal by other members of the community, and thus, must be an implicit goal of normalisation.

IV. PREREQUISITES OF INTEGRATION

1. Compatibility

The word integration implies a combining of elements, a combination into a whole, a completion. If it is argued that 'parts' or elements to be integrated are 'oil and water', thus incompatible, incapable of mutual resonance, then successful integration is axiomatically precluded. This discussion is however, not dealing with unrelated elements, we are talking about children; all children, able and disabled, who form the pattern of our society. Rhetoric may convince at a moral level but it is useful to have some visible evidence of compatibility between mainstream and special human services, an understanding of the mutuality of goals between the early childhood services and some practical approaches that enable their commonalities of practice and purpose to be actively endorsed and undertaken. Mainstream or generic programs (e.g. preschool, childcare, family day care), if of an acceptable quality, will provide 'comprehensive child development programs . . .' meeting . . . 'basic areas of need for all infants and young children'. (Appalachian Regional Commission, 1980). While the specific emphasis and manner of meeting needs may vary according to the service type, there is an overriding intention to provide 'developmental experience that 'should contribute positively to the child's total growth by including comprehensive service (e.g. educational, social, emotional, nutritional and general health)' . . . and which should . . . 'supplement . . . and complement the home, is supportive of the parent-child relationship and is suited to the child's individual needs and routines' (ibid). These intentions or goals are highly compatible with the principle of normalisation. They are almost indistinguishable from the explicit goals of integration.

Congruent goals are a valuable starting point, but to activate these goals, a framework of further prerequisites is necessary to provide the infrastructure that will ensure that individual and systematic integration works. These prerequisites or potentials are contained in the network of early childhood services. They include:

- dispersal throughout the community
- accessibility and availability
- a developmental attitude and approach to programs for children
- a flexible format which responds to the needs of the individual children
- opportunity for continuity
- the framework for the integration of the necessary extraordinary services required by the disabled child.

At this stage it may be useful to labour a point. For disabled children to be successfully integrated, the mainstream program must be one of quality.

> The quality of the program offered by an early childhood centre enrolling handicapped children is a critical factor in their growth, since these children participate as fully as possible in the overall activities provided by the centre. The same developmental limitations that more normal children may experience as a result of deficiencies in their day or preschool program will also affect the child who is handicapped . . . Variations in quality must be kept in mind when a centre is being selected for the integration of developmentally delayed children. Put more simply, a program that is inadequate for 'non delayed' children

> will also be a poor choice for children whose development is delayed.' (Galloway & Chandler, 1980)

Successful integration is dependent upon the combined availability of quality mainstream programs and the provision of associated supports.

2. **Quality**

The factors outlined as necessary for successful integration do not constitute guarantees of quality. Rather, their presence may be considered as indicators of quality but it is the dynamic of their operation, or how they combine to effect the stated goals of that child's integration, that allows a judgement of quality. Quality must be seen to happen in a practical sense. It 'must be judged by concrete indicators of the child's experience . . ., rather than by centre characteristics of presumed value' (AECA, 1986). To achieve integration requires that indicators of quality, the prerequisites or characteristics, are applied to enable the activation of the six dimensions of integration — physical, functional, social, personal, societial and organisational. (Nirje, 1980)

TABLE 1: WAYS OF ACHIEVING MULTIDIMENSIONAL INTEGRATION IN EARLY CHILDHOOD

		GOALS OF INTEGRATION	
	MEANS	STIGMA REDUCTION	COMPETENCE ENHANCEMENT
DIMENSIONS OF INTEGRATION	PHYSICAL	• inclusion - physical - attitudinal - behavioural • modification of environment to increase levels of independence	• individualized programme to foster competent use of environment - support as required
	FUNCTIONAL	• participation with needed support • interaction in real situationals	• developmental programmes with functional focus • teaching support/skills transfer
	SOCIAL	• social involvement with peers - assisted as necessary • encouragement of attitudes, manners - respect esteem	• social development support- practical skills application • experience of respect, esteem
	PERSONAL	• normal involvement and support of family - inclusion • assistance in making friends	• time • use of additional supports as necessary • assistance in establishing and managing relations with peers
	SOCIETAL	• increase awareness, understanding acceptance of handicapping condition	• opportunity/assistance in self-expression, creativity, choice making etc. as for peers • support towards optimal independence
	ORGANISATIONAL	• include in overall planning for services to increase accessibility and availability of service	• provision of adequate infrastructure of integrated supports • practical involvement of integrated services

TABLE 2: EXPECTED OUTCOMES OF QUALITY INTEGRATION IN EARLY CHILDHOOD SERVICES - EDUCATION AND CARE

		GOALS OF INTEGRATION - PRIMARY	
	OUTCOMES	STIGMA REDUCTION	COMPETENCY EHNANCEMENT
INDICATORS OF QUALITY IN INTEGRATION	Dispersal through community	• inclusion and acceptance in local area services	• provision of programmes support in "normal" environments - partial/whole
	accessability/ availability	• acceptance - belonging • personal development	• development of adaptive behaviours, attitudes, practices
	flexibility of format	• responsiveness and adaptability to individual needs	• adaptations to foster inclusion and participation
	opportunity for continuity	• "normalcy" or service availability	• flow of service to enhance development
	framework for integrated services (Extraordinary)	• establishment of patterns of community acceptance • normalized delivery of integrated services	• applied functional base for individual development • team work for greater efficiency and effectiveness
	Curriculum/ programming • holistic • competency based • developmental attitude/approach	• opportunity for child centred individualized programmes to: - ameliorate and compensate for handicapping conditions - develop self esteem - self-realization	• effective diagnostic and programming services • individualized programmes • appropriate methodologies and approaches for teaching • application of variable models of support
	appropriate and adequate staffing	• understanding and acceptance - active • time sharing	• additional staffing as required • skills sharing and adequate advisory services
	interaction • child - child • child - staff • staff - parent other professionals • staff, other professionals	• opportunities for play and friendship; communication • support • quality interaction • information sharing • partnerships and teams • family support	• programmes of assistance/ guidance • collaborative and shared approaches to meeting child's needs • effective communication and problem solving
	Administration	• planning for inclusion and involvement • efficient and effective management	• availability of resources and supports • efficient and effective management
	Evaluation	• systematic evaluation of outcomes/goal closeness	• revision, review and ongoing modification of • programmes, approaches to meet goals of overall integration and individual needs.

To effectively integrate young children into mainstream early childhood programs (that is, to ensure quality of outcomes) goals must be set that link the characteristics conditions of integration with the goals of integration. The linking of these two sets of parameters then enables individual program goals to be set within the broader societal goal of integration.

APPLICATION: The Integration Programs

The Integration Programs have been established to provide developmental and integrated support for children with significant developmental disabilities. The programs operate regionally through the specialist services provided by early childhood generic services. Where possible, there is a 'linking in' with other specialist agencies, according to the pattern of service generally followed by the generic specialist service. Parents, staff of centres and professionals aim to work in an effective communication framework, collaborating in decision-making and program development. The degree of cohesiveness in this area does vary across programs.

The Integration Programs operate within a system that contains all the quality indicators. However, individual factors are evident in variable, and not always controllable or predictable quantities. The variable factors usually are those which can be loosely collected together under the heading of resources. Some factors, such as extraordinary services, programming continuity, adequate and appropriate staffing are in short supply, in both the mainstream and specialist areas. In country regions, these factors and those of accessibility and dispersal are more difficult to provide because of distance, isolation and other transportation difficulties. Nevertheless, of the 90 or more children who have received Integration Programs support in the past two years and of the current group of about 20 children receiving programs, the outcomes are significant and heartening.

Achievement of Integration Programs to Date Include

- **Inclusion in community based program and increased access and involvement** — all children.
- **Increased acceptance and understanding** — in most cases positive attitudes were evident prior to the commencement of the program. Some assistance to integration has surfaced but this has provided the opportunity for effective communication within communities and with some staff.
- **Development of adaptive and appropriate behaviour** — Evident with all children though some improvements have been barely minimal. A subsidiary outcome in this area has been the increase of understanding of behaviour and development of means and confidence in dealing with maladaptive behaviour at the time.
- **Competency enhancement** — Evident to varying but significant degrees. a further outcome has been the growth of appreciation of the development of even the most profoundly disabled children — that is, a growth in effective and functional responses is evident in the child, the centre staff and supporting staff, other children and other parents.
- **Respite for Parents** — generally achieved.
- **Programming and evaluation** — becoming more streamlined and appropriate. Continual application of observation makes programs flexible and adaptable.

To achieve full quality Integration Programs, the following areas require further practical supports.

- Systematic availability and administrative support.
- More effective staffing approaches.

- Staff support: skills development, information
- Adequate resources: staff, extraordinary, integrated specialist support, material resources, time for planning and evaluation.

CONCLUSION

Those who are involved in Integration Programs, whether as direct support staff, centre staff, parents or advisory support are firmly committed to the competent practice of integration. The benefits to the children, families and communities are both immediate and long lasting. In the effort to help individuals towards self realisation, respect, integrity and determination, our own humanity is more fully understood and expressed. It is humanity that provides society with its social value; not the other way round.

A Supplementary Note.

Integration Programs in the Children's Services Office have expanded considerably in the past three years. From a small, almost peripheral project the Integration Programs have become the C.S.O.'s primary means of supporting access and participation in community kindergartens.

PRIMARY PURPOSES of the Integration Programs are provision of:

- **access opportunities** — i.e. to help children attend local kindergartens.
- **some direct teaching/developmental support** for skills and competencies enhancement.
- **support to participate** in the usual activities of the kindergarten.
- **support to increase independence** so that the child will continue to attend with reducing intensive direct assistance.

Integration Programs are the initiating stage in a continuum of support. It is expected that children will gradually acquire competency and independence skills that will allow them to be supported through 'regular' special education/special services support in the kindergarten. From there children will move into Education Department schools.

WHO BENEFITS?

Integration Programs are non-categorical. Children are referred for Integration Programs support if they are assessed as:

- at least 12-18 months below usual development in one or more developmental areas and where these delays, disorders or handicapping conditions indicate that the child will have significant difficulty participating in a kindergarten;
- having multiple disabilities that lead to an evaluation of significant functional delay in a kindergarten/preschool;
- having other conditions or factors affecting the child's development that strongly indicate significantly diminished capacity to participate successfully in a kindergarten setting e.g. behavioural/emotional difficulties, severe health problems, etc.

HOW IS INTEGRATION MANAGED SUCCESSFULLY?

Management of the multi-dimensional process of integration is vital to overall success. The quality of the individual program and teaching engagement is fundamental but proper regard to a range of other factors must be given: a non-integrated approach to integration will lead to

- 'ghettoing' i.e. the child and his/her program operates parallel to the centre program. Participation will be inhibited.
- a 'cycle of dependency' — centre staff become dependent upon the presence of constant support for the child.
- competition between the needs of children through the teaching program.

To activate the potential of the programs planned, careful attention to the following factors must be incorporated:

- clear communication and involvement processes
- role clarity and practices to encourage a balance between individual and group needs
- flexible decision making practices
- participatory program development and evaluation processes, including goals setting and expectations
- skills development for centre based staff to enable graduated transfer of program operation and responsibility
- continuity and integration of additional intervention services.

The ongoing management of these aspects leads to a positive evolution of involvement and participation.

INDIVIDUAL PROGRAMS

Each Integration Program is characterised by a planned approach that balances skills and competency development with participation and application opportunities. The structure of Integration Programs allows a 'focusing in' on specific developmental areas: skills development is intended to help the child participate in the mainstream.

OVERALL MANAGEMENT

An overall system of development, operation and review of programs has been instituted. While there is, of course, individual flexibility, programs in general are supported by:

- The employment, where possible, of special educators or qualified and experienced teachers and aides.
- Instituting a collaborative approach to programming and evaluation which
  - — encourages the equal participation of parents, centre staff, integration support staff and advisors
  - — highlights joint preliminary goal setting and equal participation in evaluative cycles
  - — requires the application of situational management principles and practices (e.g. environmental, supervisory, routines management) so that there is a supportive and practical context for children with special needs.
  - — incorporates evaluation of functional application of competencies — e.g. play development, independence progress etc.
  - — employs a variety of assessment and reporting procedures.
- Development of a cooperative cross regional approach to professional support and development for integration staff.

The diversity of these aspects emphasises the complexity of the process of integration programs need a focus that is broader than just the presenting needs and abilities of the child.

DEVELOPMENTS

The past two years have seen a 20% increase in funding each year for Integration Programs. This practical recognition of the importance of integration by the organisation is essential for the success of programs. Currently, 62 children are receiving support through Integration Programs which are distributed across all religions. The significant increase of availability of support to children in rural locations is of considerable importance. It is hoped that this updated information demonstrates and confirms the practical commitment of individuals, the C.S.O. and communities to the competent practice of integration. *

* (This paper was completed in May 1986, and an earlier version was published in *Early Child Development and Care*; April 1988, Vol 28, p 59-77, 1987)

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Chapter 29

MANUAL COMMUNICATION: A REVIEW OF ITS USE WITH HEARING-IMPAIRED AND AUTISTIC CHILDREN

Bronwyn Thorncraft

The first four years of a child's life are considered critical for the development of language and decisions must be made early to identify the most effective intervention method for children with a severe communication disability, if the degree of impact of the disability upon development is to be minimised. For some years, debate has continued concerning the relative merits of an oral, manual or total communication approach as the most effective method of teaching hearing-impaired children. More recently these alternative modes of communication have been considered for use with other groups of children who experience difficulties in the development of effective communication skills.

The purpose of this paper is to examine the use of manual communication for two groups of severely disabled children, namely, the profoundly deaf and the autistic. For the purpose of this paper, the deaf child will be defined as 'one who has sustained a profound (91dB or greater), primarily sensorineural, hearing impairment prelingually, caused by exogenous or endogenous factors' (Quigley & Kretschmer, 1982, p.4). The term 'hearing-impaired' and 'deaf' will be used synonymously and interchangeably. The autistic child will be defined as one who demonstrates 'a severe developmental disturbance characterised by faulty development of communication processes and . . . an inability to relate' (Martini, 1980).

The Education of Deaf Children

Historically, deaf education has been the subject of considerable controversy. This disagreement concerns the extent to which children with hearing impairments should be encouraged to communicate by **oral** (ie. speech, lipreading, residual hearing) rather than **manual** (sign language, gestures, cues, fingerspelling) means or some combination of these. The oralist tradition has been, until recently, a strong and persistent trend in the education of the deaf, both in Australia and overseas and there have been concerted attempts to teach deaf children to speak, even though this method is not a viable alternative for the prelingually, profoundly deaf child; that is the deaf child who has not heard speech. Indeed, the oral versus manual debate still thrives in schools in New South Wales where there are a number of 'oral' Support Classes for students with hearing impairments. The popularity of manual communication, however, is increasing.

The decision about whether a deaf child's communication should be oral or manual, is usually determined by the teacher's philosophy and signing skills, the area the child lives in, or parental preference. However, children who experience considerable failure using an oral method, are likely to be transferred to a manual program. This can happen early in their education or as late as secondary school age. In the experience of the author, some deaf adults, after receiving an education in the oral mode and then having contact with signers, also choose to communicate manually. These situations raise important and vital questions about the factors that should be taken into account when determining a deaf child's mode of communication. Their occurrence can be partly explained by the traditional emphasis on oral education for the deaf, but it is also apparent that inappropriate decisions must have been made before or at the time the child began school.

The Academic Achievement of Deaf Children

There is now some evidence to show that the recent trend towards the use of 'sign' in the classrooms of deaf students has not contributed to an increase in their academic performance or in their competent use of language. Although little research data are available for New South Wales, or for that matter, Australia, to document this effect with regard to academic attainment, some relevant American research has been published (eg. Pinter & Paterson, 1917; Pugh, 1946; Wrightstone, Aronow & Moskowitz, 1963; Furth, 1966; Di Francesca, 1972; Trybus & Karchmer, 1977). Indeed, it has been argued (Moores, 1970) that in their written language, deaf children of one hundred years ago were superior to those currently graduating from Deaf Education schools and programs (Moores, 1970). If those children had had a social as well as an educational profile comparable to today's deaf children, this would indeed be cause for serious concern, since it would indicate that little progress had been made in the last hundred years and that signing was not an effective method of communication. However, it is apparent that manual communication should be closely studied so that the most effective communication system is made available to the deaf child as soon as possible after his or her disability is recognised.

Total Communication

The present philosophy that underlies practice in the majority of classrooms in New South Wales is termed **Total Communication**. Defined as the full spectrum of language modes (child devised gestures, formal sign language, speech reading, fingerspelling, reading, writing and residual hearing) (Latimer, 1983), this method of communication allows the spoken language of the hearing community to be simultaneously (manually and orally) represented with the exact manual correspondence of the spoken syntactic structure. The main argument for its use, according to Reagan (1985) is that deaf children should have linguistic input that will contribute to their mastery of the English language. Reagan adds that combined with this fact is the ease of acquisition of signed English by hearing teachers. These reasons help to explain its popularity in classrooms. He concludes however, that Total Communication has not been particularly effective in providing an adequate education for the deaf, although it appears to be superior to the oral approach. Kluwin (1981) suggests that the use of a manually-coded form of English is based on the assumption that the presentation of all educational information to the child in such a form will lead to the acquisition of the language. However, according to Kluwin, this assumption is unproven.

Some criticisms of Total Communication have been made. For example, Nix (1983) believes that it has two overall detrimental effects on children's language development: first, the overall rate of transmission of the message is markedly reduced, and secondly, the normal rate and rhythm of speech is slowed down and altered.

In addition to these effects, the deletion of a proportion of the manual coding of the spoken message that frequently occurs in most Total Communication situations results in many messages being ungrammatical and inconsistent. Latimer (1983) also comments on negative aspects of the use of Total Communication. After examining the use of signs in a number of classrooms, he concluded that teachers and, indeed parents of deaf children often over-mouthed words and that their rate of signed speech was very slow. Many were not competent in sign language and, therefore, often unable to produce syntactically and grammatically correct utterances. In addition, to counter-balance the slow rate of expression, they omitted functors, bound morphemes and/or determiners. These occurrences are, no doubt, very confusing to the deaf child who, in many cases, must teach the parent or teacher how to sign.

In relation to the problem of production rate associated with signing English, Nix (1983) notes that the rate of articulation for speech without signs is twice the rate of articulation of signs alone. The significant difference in production rate of signs versus spoken words causes major difficulties to the deaf student when these modes are forced to express the same information. Kluwin (1981) recognises that some type of reduction in the spoken language used must be taking place.

Clements and Prickett (1986) view the use of Total Communication in classes as having become as restrictive and repressive as the tradition of oralism. The similarities that exist between the two include:

1. an insistence that all children communicate in English,
2. an over-expenditure of time in the teaching of English to the exclusion of other essentials, and
3. a restriction upon the child's progress in learning to read and write English.

It becomes evident that the method of communication employed in deaf classrooms can be, in many cases, ineffective, confusing to the students and often incorrect. It is important, then, to identify a more efficient system of communication for use in schools so that deaf students are no longer seriously handicapped in their education. The profoundly deaf population is a cultural and linguistic minority group with distinctive educational needs. Decisions concerning the mode of communication have important educational consequences.

Auslan (Australian Sign Language — A.S.L.) The sign language used by Australian deaf adults is known as Auslan (Australian Sign Language). Its American equivalent is known as Ameslan (American Sign Language). The native languages of the deaf communities have features of the language in their own right, although there are a number of significant differences between them and spoken English. Deaf Sign Languages have the following features:

1. They are not universal. A number of communities have a different sign for the same concept.
2. Different syntactic rules are followed and few determiners are used.
3. They are a visual language with a large number of iconic signs.
4. The languages use a number of mechanisms that provide a grammatical structure as well as conveying meaning, degree, stress and tense.
5. Degree can be conveyed by the size of the configuration, just as stress in the hand movements can convey mood.

Baker-Shenk (1985), reporting on the facial behavior of native signers, stated that the signed language of the deaf community uses the signer's body much more fully than spoken languages. She commented that research in the area was only new and, by investigating the gestural and facial behaviours of their students, teachers of the deaf could be provided with valuable information that could contribute to the education of deaf children.

An important feature of Auslan is that, because of basic differences in syntax, it cannot be paired with speech. For example, the Auslan communicator can present two or more concepts at the same time by using two hands. This feature makes its rate of transmission similar to that of spoken English. However, it is this feature that makes it incompatible with the philosophy of Total Communication, which requires the communicator to make use of all possible modes including the spoken word, for the communication of English. Oral communication requires the speaker to use words in a syntactic sequence to convey meaning; an Auslan signer, for example, may be able to communicate the same words and their meaning in just one movement. It therefore becomes apparent that a sign language such as Auslan is incompatible with the philosophy of Total Communication as it is practised in most schools in New South Wales.

Currently, Auslan is not officially recognised in N.S.W. schools as an appropriate language for deaf students. It is rejected by educationalists and parents for a number of reasons. There is little known about the language. There are negative attitudes towards it and doubts as to whether or not it has status as a language. Furthermore, there exist barriers between schools and members of the deaf community who are users of Auslan; deaf adults have very little influence on how deaf children are educated. The reasons for such barriers are numerous. Most deaf children are born to hearing parents and, at the time they are enrolled in the school system, have very little language. So these students receive instruction 'in a language that they don't understand and know nothing about: English. They are passive victims of an education that's conducted in a language they do not know and do not learn' (Rigg, 1986). Evidence to support this claim is provided by research into the academic skills of deaf students. For example, Furth (1973) in a study of deaf and hearing children in the USA, showed that the average reading score of the deaf children increased from only grade 2.6 to grade 3.4 between the ages of 11 and 16.

Research into the comparison of academic performances of deaf students of deaf parents and deaf students of hearing parents also has significant implications for the future of Deaf Education. (It should be emphasised at this point that deaf children of deaf parents have the benefit of natural language acquisition through the use of an intact signing model and, in many cases, Auslan, Ameslan etc.) According to Moores (1978), research reported by Stuckless and Birch (1966), Meadows, Greenbug, Erting and Carmichael (1981) and Vernon (1970) provides evidence for the assertion that the deaf child of deaf parents has a significant educational advantage. For example, Vernon (1970), comparing 32 deaf children from hearing families with 32 deaf children of deaf parents, found the latter group were superior to the former group in academic performance and achievement. These results raise important questions for educationalists; is Auslan a more effective system for the deaf student; and is exposure to an intact signing adult model (whether it is Total Communication or Auslan) just as effective?

The Importance of Early Intervention

Deaf children of deaf parents have access to a visual communication system from birth. The language of these children develops in a similar manner to that in which hearing children acquire vocal auditory communication (Stuckless & Birch, 1966). All children need an intact appropriate language model in their formative years. The problem is that hearing parents are unable to act as proficient and grammatically correct signing models for their deaf children when they are young, although some parents with years of practice, do become proficient (Nix, 1983). However, there is evidence that children progress better when manual communication is employed by their parents. Stuckless and Birch (1966) investigated the influence of early manual communication and deaf children's subsequent acquisition of intelligible speech, reading ability, speech reading, written language and psycho-social adjustment. The results of this and other studies (eg. Howse, De Salle & Fitch, 1972) indicate that early manual communication is positively correlated with academic performance and psychosocial adjustment.

Moores (1978) has reviewed the possibility that a critical time, or at least an optimum period, exists for language acquisition. The specific ability to develop language appears to peak around three to four years of age and tends to decline thereafter. Perhaps any school program for deaf students will fail if the students do not have access to language when they are young. Hearing children receive input from birth. The lack of effective communication for deaf children in the first five years has tremendous implications for later development.

It is vital that decisions regarding the communication mode a hearing-impaired infant uses should be made as early as possible. It is important for a child to receive information from the time of birth in order to develop psychologically and linguistically. For a profoundly, prelingually deaf child, sounds alone are ineffective and a supplementary method is needed so that full communicative exchanges can occur. Jacobs (1974, p.14), a deaf adult, comments that 'when you consider untrained and undisciplined deaf infants or small children, it seems ridiculous if the parents attempt to communicate by talking'. Lip movements convey very little meaning when there is no adequate language base to fill in the gaps. There is some evidence to support this claim. For example, in an Australian study, Mohay (1984) studied two deaf subjects who attended an oral pre-school and were not exposed to manual communication. They had no other handicap. Mohay noted that both subjects developed a rudimentary communication system derived from fragmented and incomplete language models from the hearing population. However, the subjects' language was well below their hearing peers of the same age. The critical importance of language acquisition for the later progress of the child, at school, is revealed by considering cases of its absence, as with deaf children born to hearing parents.

A Bilingual Education

Alberto, Garrett, Briggs and Umberto (1983) state that sign as a communication mode has limitations and points out that if the communication is restricted to a familiar audience, then it is not truly functional. A response to this attitude has been made by a number of communities and educationalists. Bockmiller (1981) believes that a sign language such as Auslan cannot continue to be thought of as a substandard version of English. He argues that it should be accepted as a separate and distinctive language. A recent trend in thinking is that because deaf Sign Language is recognised as a language in its own right, deaf children in schools should be taught using bilingual methods. Reagan (1985) suggests that the deaf are an ideal population for employing such an approach in their education. A discussion paper (1982) presented by 'Concerned Deaf of New South Wales' supports this viewpoint, stating that the education of the deaf could almost be thought of as bilingual. If this is so, then deaf children in New South Wales need to be given the opportunity to develop their native language, that is Auslan, as well as to learn to read and write in English, as English remains the written language of the deaf community and is an indispensable key to the hearing world.

The Autistic Child

The previous discussion focused on issues that are unique to the deaf population. Consideration of the use of Deaf Sign Language with a language-disordered, hearing group such as that represented by autistic children is not really appropriate because such children are able to receive the total message conveyed in speech utterance. Total Communication or Makaton (a modified sign system) may be a more appropriate method for children who are able to receive auditory input, as both spoken and visual language symbols can be presented simultaneously.

Autistic and deaf children, of school age share many common attributes. Both groups are usually language impaired and, if no other handicap is present, have intact and well developed motor skills. However, there are also a number of differences that distinguish the two groups, and a summary of these is represented by the following:

Deaf Child	**Autistic Child**
* desire to communicate	* no desire to communicate
* very limited auditory input but will attempt to process it	* auditory input is received but not processed
* opportunity to belong to a cultural minority	* no cultural implications apply
* generally have access to a signing community	* access to signers is limited

As a result of the differences identified here, some unique considerations must be taken into account when decisions are made concerning the adoption of a non-vocal communication mode for an autistic or deaf child. For example manual communication is often selected for an autistic child when vocal communication is not suitable, and some research has been reported on the use of a manual mode with autistic children. Ruder and Stemel (1978), reported a study which examined the effect of a combination of manual and spoken modes on the language development of a small group of autistic children. In this study, three conditions were used:

1. Manual sign plus the spoken label
2. Manual sign plus the spoken label where child was not required to sign
3. The manual sign was omitted.

Results suggested that the first category (sign plus speech) yielded the greatest verbal response. Similarly, Konstantareas (1984) tested to determine if signs facilitated the acquisition and recall of expressive language in a sample of 14 autistic children aged between 3.10 and 11.01 years. All subjects' speech was telegraphic. She found that the findings supported the main prediction, namely that signs were facilitative for the development of speech.

Similarly, Carr (1979) found that by using sign with mute autistic persons, speech was shown to sometimes emerge. In a review of relevant literature, Konstantareas (1985) concluded that signing should not be used as a main vehicle for communication, but as an aid to more complex speech production for those children who have useful but limited speech.

In a recent study, Wagenen, Jensen, Worsham and Petersen (1985) used simultaneous communication to teach difficult verbal discriminations to an autistic, developmentally disabled child. They proceeded to teach colours to a vocal autistic boy, who could not receptively or expressively discriminate pink/purple/brown, using a vocal stimulus only. The intervention strategy entailed teaching manual sign with the oral stimulus in the following sequence:

1. The boy learnt the discrimination.
2. The sign was then blocked.
3. The boy could then discriminate the colours both receptively and expressively without manual cues.

The explanation for the superiority of sign and speech over speech alone for teaching receptive and expressive language to autistic children may be that sign provides extra information that facilitates learning. In terms of clinical implications, these findings add to the options that should be considered when helping language-impaired children who have some spoken language to expand their utterance and make their language more complex and rich.

However, the question remains: What happens when speech is not present? Schuler (1985) presents a comparison of two autistic non-vocal children and a way of determining the best mode of communication for them. She observed two children who possessed a number of similar behaviours (eg. both threw tantrums, were non-vocal, and had management problems and aberrant behaviours). Tim (Subject 1), was a non-vocal autistic child who had been in a signing program for two years and had learnt to use five signs. However, these signs were not used in a meaningful way; the boy communicated with a passive gaze, re-enactment strategies and proximity. He had no pointing behaviours. Laura (Subject 2) had intonation in her voice, possessed pointing behaviours and used facial expression to communicate a variety of expressive messages. It was decided, based on the observations made, that Laura should be introduced to sign language but, because of the limitations inherent in sign, efforts would also be made to teach her to read. The signing program for Tim was discontinued. It was decided that he should be taught pointing behaviours which are the pre-requisite skills that need to be present before picture communication could be introduced.

The use of a picture communication was studied by Lancioni (1983). Like Schuler's subject, Tim, the subjects that he selected had been in a signing program and had failed to begin to communicate by signs. Lancioni introduced a highly structured pictorial communication program, and subjects were successfully trained, acquiring thousands of iconic picture representations.

A similar result is reported in a research project at North Rocks School for Multi-handicapped Children (Thorley, 1986). A signing program was unsuccessfully introduced to an autistic deaf child (S), who could not associate signs with meaning and often lapsed into a 'state of confusion' when new signs were introduced. The subject was then successfully placed on a printed word communication system. After a reasonable time, sight vocabulary was established, signing was re-introduced. S's signing then developed rapidly and confidently and eventually began to outstrip his reading repertoire.

It becomes apparent that language training programs based on speech alone can have limited application. Speech has limitations for language disordered autistic children, although speech alone can be used successfully with some. However, there is considerable individual variation in responsiveness to it. On the other hand, there are certain characteristics of Sign Language that appear to render it particularly well suited to the peculiarities and communication deficits of autistic children. These are summarised in the following:

- **Signs possess iconicity** which makes them easier to remember and recall.
- The **speed of production is slower**. Signs are produced at half the rate of speech and even though they are transient, they are less transient than speech.
- **Signs can be shaped** and they are amenable to direct manipulation.
- It is **easier to discriminate visual hand movements** than it is to discriminate fine sounds.

Even though the above properties of signs provide some autistic children with a viable alternative communication mode, they are not a suitable communication mode for all non-vocal children. This limitation results from the following factors:

- **Signs are transient** (unlike pictures).
- **Not all signs are iconic** (unlike pictures).
- There is a **great variance in signing** between two individuals and this may cause confusion for the child.
- Some **children may not have access to signers**, other than the instructor, and this will not encourage the student to communicate.

CONCLUSION

Sign language is not necessarily the most effective means of communication for language-disordered children and it is evident that when selecting a non-vocal communication mode for a child it may be necessary to develop the joint use of two methods, eg. vocal/sign, sign/picture; and for the deaf child, Auslan/written English, so that the disadvantages of one system can be counterbalanced by an augmented system.

Determining the most suitable communication modes for language-impaired students involves complex decision-making that cannot be undertaken by any one person. Specialist teachers, family and even community opinions need to be consulted, as the nature of each child's handicap will have considerable influence on the mode selection. The decision map needs to be detailed and thorough to ensure correct selection. Alberto, Briggs, Garrett and Umberto (1983) have proposed a seven-step model to assist in making a logical, systematic communication programming decision;

Step 1 Is a non-vocal system appropriate at this time?
Step 2 Should a verbal facilitation program be initiated?
Step 3 Which non-vocal category should be selected?
Step 4 Within the chosen category, which language system should be selected?
Step 5 What will be the means of access?
Step 6 Which vocabulary items will be selected for initial vocabulary?
Step 7 What is the order of initial instruction?

The steps outlined here are detailed and present an overall view of the considerations that need to be made when selecting a communication program for a child. However, there is no indication at any point that decisions could and should include a combination of non-vocal modes (for example, Auslan and print) so that the student can have access to two distinctive but complementary communication systems. So, while the model does identify some important steps in the decision-making process, any professional, when determining a suitable mode for a particular client, must also consider all aspects of the available systems. In addition, consideration must be given to the language, cognitive, social, emotional, cultural and physical characteristics of the child. This is done through consultation with all relevant professionals, including speech pathologists, audiologists, teachers, as well as with the child's parents and in some cases members of the wider community and, in particular, members of the community of deaf adults.

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Chapter 30

TEACHER TRAINING FOR EARLY CHILDHOOD SPECIAL EDUCATION IN AUSTRALIA

Julie Campbell

In the last ten years an increasing amount of public and professional attention has been directed toward the needs of young children with developmental disabilities. This has lead to the establishment of early intervention programs funded variously by Federal, State, and local agencies (Watts, 1981). Early intervention programs are diverse in structure and in the population serviced, but can be roughly divided into two groups: those largely home-based and serving children aged 0-3, and those largely centre-based and serving children aged 3-5. (The ages given are developmental approximations.) Staffing for these programs draws on a variety of professional skills and training, for which there seem to be few specifically designed degree or diploma courses.

Three themes underlie this review of what is currently available in Australia as professional preparation for work in early intervention, and what is currently suggested as desirable in the research literature. The first is to do with the knowledge base of such preparation, in particular the focus on normal child development, the second is the skills base and the extent to which particular technologies can be generalised to babies and toddlers, and the third is the role of 'teacher' which may or may not transfer out of classroom settings into community-based and family-oriented settings.

Before addressing the particular problems of teacher training there are two major concepts which need to be clarified. The concept of the 'whole child' has become an unquestioned truism in the field of early childhood education. Applied to normal child development it endorses a rather global view of a wide range of behaviours. Where it is questioned in the literature, it is in terms of precise relationships between behaviours (Ungerer and Sigman, 1984) and between behaviour and context (Maccoby, 1984), rather than its general appropriateness as a paradigm. Applied to children with developmental disabilities, its appropriateness has interesting implications. If all developmental processes are interrelated as the paradigm, and even common-sense, would suggest, then disabilities in one developmental process would affect other developmental processes. Place the 'whole child' in the dynamics of an ecological context and these 'ripple' effects have the potential to become tidal waves (Papousek and Papousek, 1983). There has been misleading argument in the past (Karmel, 1973) that children impaired in one aspect are normal in every other way. While this view might have been offered to aid the process of normalisation, it matches neither theory nor reality and provides a poor basis for planning service provision. Following the paradigm of the 'whole child', intervention must involve all developmental processes, not just a supposedly separable disability, **and** in the context of home and family. The implication for all staff, therapists and teachers, is that a highly specialised training in, say, motor development or teaching of the deaf, may not readily be adaptable to a more comprehensive and complex view of development. Further, it is entirely possible that neither teaching nor health professionals have had training incorporating comprehensive views of child development (Freund, Carey & Bradely, 1982).

The concept of 'education' has had a much harder time in the field of early childhood than has the 'whole child'. Most of the difficulties have arisen over the translation of aspects of schooling and group instruction (which we associate with education) to under-school-aged children. The translation has been a little easier where children are in group settings of some kind. It has been more problematic where children are at home, under the age of three, and not taught by a teacher. Since these three aspects are common features of early intervention programs, it would appear difficult to link early intervention with the conventional structure and function of education. This conventional view of education works in two different directions, discouraging education authorities from extending their responsibilities to children younger than age of school entry, and discouraging health and welfare agencies from including an educational component in early intervention programs because of its association with rigid instructional practices.

A further difficulty may lie in relating early childhood education to special education. Kauffman (1980) views the strains here as the products of contrasting concepts of childhood; a holistic childhood-unique concept as against as adult-analogous childhood-continuous concept. These differences may show up in different approaches to teaching and expectations of developmental change. Decisions about desirable teaching outcomes must address, sooner or later, whether development is to do with quantitative or qualitative change, and how instructional strategies are best fitted to basic concepts of childhood.

The early learning of the competent infant (Stone, Smith and Murphy, 1974) and the qualities of early experience (Fogel, 1984) are now well documented. Although there is general agreement (Yarrow, 1979) that early negative experiences are not irreversible, there are more recent suggestions (Bricker, Bailey and Bruder, 1984) that early experience may be particularly important for children with organic impairment because of the constraints on subsequent compensation. Since developmental disabilities will affect learning and experience from birth, it would seem that an educational program is needed from birth. Where social interaction is seen as the interpretive mode for learning about self, others and the world (Maccoby, 1984), the limitation of such education programs to the 'teacher' makes little sense. All those who spend significant time with the child are educators. Thus educating the educators becomes an essential part of early intervention and a role for which teachers need preparation and training.

Through this discussion of conceptual issues it can be seen that teacher training for work in early childhood special education must encompass an understanding of theories of childhood, child development, and education, with a widening of conventional views of the roles of 'teacher' and 'teaching'.

STAFFING OF EARLY INTERVENTION SERVICES IN AUSTRALIA

In the period 1979/80 a major survey of early intervention was undertaken by the staff of the Schonell Centre (Watts, 1981). The purpose of the study was to survey current programs, sample opinions of parents involved, and identify related issues. Information about staffing was gained from 134 programs and services. All of these were staffed by a variety of health and welfare professionals and 97 (73%) included teachers in the staffing. No details of specific qualifications are given. Among the issues identified were the poorly defined concepts of interdisciplinary or transdisciplinary teams and difficulties of 'meshing traditionally separate approaches to service delivery' (Watts, 1981, p.189). A recommendation was made for the provision of essential post-graduate and in-service education for the range of staff involved in early intervention, to foster the required skills, especially those involved in teamwork.

STAFFING OF EARLY INTERVENTION SERVICES IN N.S.W.

Based on data collected in 1983/4, the N.S.W. Early Intervention Association Directory (1985) lists 63 programs in 10 regional divisions. Details are available for 56 of these programs which indicate that 34 serve children 0-5, eight serve children 0-3, and 14 serve children 3-5. Nearly all programs employ at least one special educator, but description of professional qualifications is not sufficiently precise to do more than make some general observations about staffing patterns. For both the 0-3 and 3-5 programs there are some staff with combined special education and early childhood qualifications and also teams where special educators and early childhood educators are working together. These features are less apparent in the 0-5 programs where the most common pattern seems to be that of special educator plus therapists. It is possible that these differences reflect aspects of the initial funding priorities, or even lack of available personnel, especially in country districts. The following heartfelt comment is made with one of the entries (N.S.W. Early Intervention Association, 1985).

> 'Successful at this time. Need for preschool special education teacher. Often difficult working in isolation, i.e. country area. Very keen on seminars and workshops in Newcastle and Sydney.'

Without any way reflecting on the qualities of staff and programs, it would seem most likely that the particular competencies required for working in early intervention have been acquired on the job rather than through pre-service training. A brief review of trends in teacher training will indicate why this might be so.

Teacher training

In a recently released Commonwealth Schools Commission report on special education (Andrews, 1985), early special education is supported in general terms as an important area for Commonwealth funding. The report makes recommendations for teacher training, which follow similar proposals made by recent State reports (N.S.W. 1982, Tasmania 1983, Queensland 1984, Victoria 1984, Western Australia 1984).

Training needs are seen to include a basic pre-service course for all regular classroom teachers, a course for teachers of a severely disabled, regular in-service and post-experience courses, and in particular the report notes that:

> 'Special education teachers . . . are ill prepared for work within the transdisciplinary approach which is vital for effective education of most children with disabilities. Personnel trained in health related disciplines, such as speech pathologists, also need to receive training in developmental disabilities and education approaches in their undergraduate studies.' (Andrews, 1985, p.85)

In the report on Integration in Victorian Schools (Collins, 1984) there are very specific recommendations for mandatory units of study of special education of at least 84 hours and 45 hours to become part of the Dip. Teach. and Dip. Ed. courses respectively, and for such units to become pre-requisites for employment with the Education Department by 1988.

The relationship between such policy recommendations and current teacher training programs is obscured by the many pressures and funding cut-backs being experienced. In N.S.W. where the report (Strategies and Initiatives for Special Education in N.S.W., 1982) was substantially rejected by the Minister, teachers and teacher educators understandably feel a little uncertain about the future of special education.

In most existing pre-service teacher education programs there is some course work related to the needs of exceptional children. However the titles of such courses (compensatory education, learning disorders, children with learning difficulties, children with special needs) are indicative of a wide range of views about the characteristics of the children that it is assumed graduating teachers are likely to encounter (Haskell, 1977). An alternative approach is to provide an overview of handicapping conditions, seeing children's needs in terms of categories such as mental retardation, physical handicap and so on. Neither of these approaches encapsulated in the single semester course appear to have any necessary connections with the study of normal child development. One explanation for this may lie in the gradual disappearance of child development courses from teacher training.

Where early childhood education has been merged or subsumed by a primary education department or institute, loss of child development, family studies and associated fieldwork has been a frequent result. Freda Briggs, reporting on a recent Australia-wide survey (Briggs, 1984), comments on the fact that, amongst teacher training institutes offering early childhood programs, course-work in child development varied from part of the first semester to 26% of the total program. Only three of the fifteen programs surveyed offered a major core component in child development. A typical component in primary education programs is a single semester on Human Development or Life-span Development offered at an introductory level in the first year. Where teacher education follows the now preferred pattern of three years' full-time (Stage one) plus one year's experience (Stage two) plus two years' part-time study (Stage three) leading to a Bachelor of Education degree, there would appear to be opportunity at the Stage three level to extend and consolidate earlier studies. However, since Stage three must relate to Stage one, the quality of the former is very much dependent on the latter.

First degrees offered by universities which offer a special education specialisation have similar problems to those found in teacher training programs. Through careful selection of courses a student may include (e.g. at Macquarie University) up to four single semester courses relating to special education, but there are no prerequisites for the study of child development. In effect, neither pre-service teacher training, nor first degree offer any certainty of a sound knowledge of child development.

IN-SERVICE AND GRADUATE TRAINING

The appended Table lists all the programs in Australia which appear to offer qualifications in special education (Directory of Higher Education, 1985). Most graduate diploma courses and undergraduate specialisations are offered to teachers currently working and/or with some specified amount of teaching experience. As one year full-time or two year part-time patterns of study, graduate diplomas offer an accessible and field-related opportunity for a specialised diploma. Most courses are non-specific, i.e. planned to be relevant to a wide range of special education classroom situations. A typical example would be that offered by Darling Downs I.A.E. (Darling Downs Handbook, 1985). Semester one: Introduction to the Exceptional Child; Developmental disorders. Semester two: Educational Assessment and Reporting; Special Education Instructional Methodology. Semester three: Diagnostic-prescriptive Teaching I; Diagnostic-Prescriptive Teaching II. Semester four: Issues and Principles in Mainstreaming; Elective — choice of four, one of which is Early Childhood Education for the Handicapped.

From the information available in directories and handbooks, it would seem that the information base, competencies, and roles required by teachers working with developmentally disabled children aged 0-5 are not specifically provided for by either pre-service or in-service training. However, it must be noted that the full range of possibilities is not always apparent from the perusal of handbooks and directories. Many teachers currently working in early intervention programs may have found alternative tracks to give them the kind of preparation needed. Further, omissions and errors are always a problem. The current Directory of Higher Education omits the program offered by my own Institute (Institute of Early Childhood Studies, Sydney College of Advanced Education). This is a Graduate Diploma in Educational Studies with a major option in early childhood special education. A revised version of this program has been offered in 1984 and 1985 which aims to provide for workers in early intervention and integrated early childhood services. The following four year-long courses make up the early childhood special education pattern: Infant and Toddler Development, Administration in Early Childhood Special Education, Curriculum Development in Early Childhood Special Education, Instruction Strategies in Early Childhood Special Education.

NON-AWARD IN-SERVICE EDUCATION

Professional development through non-award in-service courses is well-established as an important contribution to teacher expertise. Such courses may range in length from short courses e.g. the courses associated with the Learning to Talk Program offered by the Special Education Centre, Macquarie University, to one- or two-session workshops and seminars, such as those typically offered by the Institute of Early Childhood Studies Continuing Education Program. The courses may be organised as part of Continuing Education programs at a tertiary institute, or by major employing bodies like the Kindergarten Union. Regional in-service programs may also be organised by children's services advisors in response to staff interests. Professional conferences and seminars organised by groups like the Early Intervention Association of New South Wales are another important way of up-dating information and skills and sustaining a professional support network.

The Report to the Schools Commission (Andrews, 1985) expresses some doubt about the existing organisation of in-service courses and urges closer links with tertiary institutions and the setting of common objectives to improve professional development programs. The Institute of Early Childhood Studies Continuing Education Program has a steering committee whose members include representatives from the field. In this way courses can be planned that are relevant to existing needs and also a source of new, research-based information. The Collins report (1984) makes a strong claim for parent access to in-service education. While this relates particularly to the report's proposals for integration, the general principle of non-exclusive in-service education raises some interesting questions about Education Department In-Service funding and a broader view of education and the educator. While planners of courses may demur at the prospect of course participants with a non-uniform knowledge base, the advantages of a group who can exchange experiences from either side of the professional-parent fence cannot be over-estimated. There is a real need for parent participation in in-service to be seen as fully legitimate, without however making such involvement any kind of prerequisite to service delivery. Regular teachers still need to be tempted to Education Department in-service courses through class relief, refundable fees, and in some instances crediting of their increase in professional expertise. Investigation of access to in-service programs is needed for those working in early intervention programs **not** funded by major authorities.

One final mode of in-service education that has particular relevance to early intervention services is that of an on-site program. This involves bringing someone with expertise to the program centre and freeing time so that all members of the team can benefit as a group and gain what is particularly relevant to their situation. Such a program also lends itself to parent participation, and offers opportunities for in-house evaluation. Ideally, such on-site programs should be budgeted for as an intrinsic part of the service to complement and strengthen what is gained from other kinds of in-service education.

CURRENT VIEWS ON EARLY CHILDHOOD SPECIAL EDUCATION

It will be apparent that, in reviewing available teacher training, the three themes mentioned at the beginning of the chapter, knowledge base, skills base, and role diversity have guided discussion. These themes can be amplified by recent findings in the literature. Current interest in handicapped infants has lead to the reaffirmation of the need for detailed information about normal child development, especially of infancy. Garwood (1983) notes simply that 'such knowledge is the foundation of intervention' (p.69).

Dissatisfaction with both special education training and early childhood training (Beckman and Burke, 1984) leads to consideration of what needs to be different about early childhood special education. Beckman and Burke (1984) suggest that sophisticated teaching skills, comprehensive understanding of handicapping conditions, understanding of health and medical problems, and abilities to work with families are unique requirements. Mallory (1983) argues that a new discipline blending early childhood and special education has evolved which requires new training models. The model for a masters level program that he puts forward emphasises clinical and liaison skills within a developmental and ecological framework. His recommended program of studies includes the following: Child Development for the Early Childhood Professional, Environments for Early Childhood, Contemporary Influences in Early Childhood Education, Assessment in Early Childhood, Introduction to Young Children with Handicaps, Diagnosis and Education Planning for Young Handicapped Children, and Supporting the Parents of Young Handicapped Children (Mallory, 1983). Zeitlin, du Verglas and Windhover (1982) suggest competencies in the areas of child development, family involvement, program implementation, assessment and administration as guidelines for preparation of infant interventionists.

These are echoed by Geik, Gilkerson and Sponseller (1982) in their discussion of roles and competencies, which they delineate as those of facilitator/consultant, infant specialist, parent educator, team collaborator, and program developer and advocate. Each of these roles has an accompanying list of up to fourteen competencies to be achieved through coursework and field placement in the Master's program at Wheelock College, (Boston, Mass.).

Fewell (1983) lists the skills of the infant special educator under eight headings: infant assessment, environmental assessment, teaching skills (infants and parents), environmental arrangements, curriculum implementation and evaluation, infant development, program administration, and program evaluation. She notes that while there will be some skills in common with other special educators, the content and information base of instructional strategies will be quite different. There will be a different approach to assessment, a much greater amount of time spent with parents, a different appreciation of development in curriculum and a broader understanding of the roles the infant educator must play. Bricker (1976) describes these roles as those of 'evaluator, generator, trainer, organiser, and synthesiser.' (p.88)

Several issues are raised in discussion of these aspects of teacher training. The complexities of working in a team, however constructed and organised, show up clearly in the process of student placement for field work (Geik, et al., 1982). Many such teams work so well that an outsider has difficulty in understanding the implicit relationships and transactions. Much of this level of day to day functioning may be idiosyncratic to the team and the program therefore difficult to transfer to other settings. Other problems arise when relationships with a family carefully nurtured by a team member must be arbitrarily opened up to include the student. Mallory (1983) also notes the difficulty of finding good role models with adequate professional training. The need for ongoing in-service for intervention staff is relevant here.

Close matching between course content and fieldwork objectives is seen as essential in training programs (Walker-McCollum, 1982), together with objectives which match the timespan in which it might be expected that children's behaviour will change, e.g. a two week block practicum may not enable a student to see any outcome of her work. It is interesting to note that there is discussion now, not just of lists of competencies, but on the details of just how those competencies are achieved and evaluated and where the practical difficulties lie in implementation of course objectives.

SUMMARY

Teacher training for early childhood special education has been a concern of those in the field, which until recently has been voiced in general terms rather than specific requirements. It appears that most effort has been directed towards identifying the client groups and establishing services, with only belated attention to the specifics of staffing requirements. As more is known about young handicapped children, their needs for early intervention and special education can be more precisely described and the qualities of staff more closely matched to meet those needs. There is now sufficient information available to mount good training programs for early childhood special educators. Issues relating to the content, competencies and practicum have been identified. However there are two major areas of uncertainty which may well inhibit the development of training programs. The first lies in the area of liaison with workers in the field and lack of clear guidelines on just what kind of role or roles an early childhood special educator is currently undertaking and might reasonably be expected to continue to undertake. The second, more intractable problem, lies in the fragmentary and ad hoc nature of early intervention services in some Australian states. This means that there is no major employment body to whom those responsible for training programs might relate with a degree of mutual accountability and responsiveness.

Further, one may wonder why a teacher would undertake additional training for employment in an area which offers little security of tenure, because of the vagaries of annual funding, and limits to job satisfaction because of the difficulty in attaining long-term goals. Continuity in long-term planning and funding commitment is an essential requirement for staff **and** program development.

TABLE I

Courses offering preparation for special education in Australian universities and colleges of advanced education.

Place	Undergraduate U.G.I.	Graduate Diploma	Post Graduate Degree
Bendigo		G.Dip. Special Assistance	
Brisbane CAE	Dip.Teach.(Prim. & Special Schools)	G.Dip.Special Ed.	
Canberra CAE		G.Dip. Special Ed.	
Darling Downs		G.Dip. Teach. (Exceptional Children)	
Flinders U.	B. Spec. Ed.		M.Ed. (Spec.Ed)
James Cook U.	Dip. Spec.		M.Ed. (Spec.Ed) (Hons)
Kuringai CAE		G.Dip.Ed.Studies (Spec.Ed)	
		G.Dip.Ed.Studies (Learning Diffs.)	
Macquarie U.	B.A.Dip.Ed.-specialisation		M.A. Spec.Ed.
Melbourne CAE		G.Dip.Spec.Ed	
Melbourne CAE I.E.C.D.		G.Dip.Spec.Ed	
Mitchell CAE	Dip.Spec.Ed.(in-service)	G.Dip.Spec.Ed.	
Monash B.Ed.-specialisation		M.Ed.Studies-specialisation	
	B.Spec.Ed.(in-service)		
Nepean CAE		G.Dip.Ed.Studies (Hearing & Visual Impairment)	
		G.Dip.Ed.Studies (Spec.Ed)	
Newcastle CAE	Dip.Spec.Ed.(in-service)	G.Dip.Ed.Studies in Spec.Ed.	
Newcastle U.	B.Ed.Stud. (specialisation)		M.Ed.Studies-specialisation
S.A. CAE	B.Ed. in-service		M.Spec.Ed.
S.C.A.E. Institute of Early Childhood Studies		G.Dip.Ed.Stud. (E.C.Spec.Ed)	
Tasmania U.	B.Spec.Ed. (in-service)	G.Dip.Spec.Ed.	M.Spec.Ed.
Tasmanian CAE		G.Dip.Spec.Ed.	
Vic. College Burwood	B.Ed. (Prim) specialisation	G.Dip.Spec.Ed.	
Vic. College Rusden		G.Dip. Learning Difficulties	
W.A. CAE Churchlands		G.Dip.Remedial Ed	
W.A. CAE Mt. Lawley		G.Dip.Spec.Ed.	

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Chapter 31

ALTERNATIVE AND CONTROVERSIAL TREATMENTS IN DOWN SYNDROME: ARE THEY EFFECTIVE AND WHY ARE THEY POPULAR?

P.J. Foreman

Diagnosis of a congenital disability in a child is often associated with poor prognosis. For some conditions, medical treatment can relieve symptoms. Surgery for cleft palate, replacement therapy for hypothyroidism and diet control for phenylketonuria are examples of such interventions. There are other conditions for which intervention either provides no obvious change, or is able to produce change which is both slow to occur and difficult to measure.

Down syndrome is a condition which seems likely to respond to direct medical intervention. Children with Down syndrome do not have any obvious physical deformity. Their appearance at birth is relatively normal. Subtle signs may be apparent to medically-trained staff but difficult for inexperienced persons to observe. Development in the first months is close to that of age peers. It is reasonable for parents to expect Down syndrome to be more amenable to treatment than, for example, spina bifida, cerebral palsy, or other congenital disabilities.

The major breakthrough in the study of the causes of Down syndrome came through the use of cytogenetics and identification by Lejeune, Gautier and Turpin (1959) of an extra chromosome in persons with the syndrome. With the identification of the trisomy, it was possible to further identify Down syndrome resulting from primary (standard) trisomy (93-96%) (Hook, 1981), translocation (3-5%) and mixoploidy (mosaicism, 1-2%) (Hamerton, 1981). Although the cause and definitive method of identification of Down syndrome was thus established as the presence of additional chromosome 21 material, these findings led to the questions of why non-disjunction occurs and of why the extra chromosome material leads to the physical symptoms associated with the syndrome. At present, identification of a trisomy condition has no direct implications for treatment. The major clinical consequence of the understanding of the chromosomal origin or Down syndrome has been the ability to detect the disorder prenatally.

A major focus of research in Down syndrome has been the study of the physiological and biochemical characteristics of persons with the syndrome. Such research aims to improve the treatment of the disability and, possibly, to relieve the clinical characteristics. However, in spite of a large volume of research, there have been few conclusions related to treatment. Those suggestions which have been produced have received varying degrees of acceptance and, according to Lejeune, Prieur, Rethore, Aurias and Raoul (1983), there is no claim about medical treatment or cure which has withstood scientific scrutiny. Despite the apparent lack of a proven treatment, some parents of children with Down syndrome understandably continue to seek and initiate forms of non-orthodox treatment, frequently against professional advice. Conflicts between parents and professionals can arise because the two groups use different criteria for evaluating the effectiveness of a procedure, and because professionals are sometimes perceived to be restricting the ability of parents to make treatment decisions for their children. For example, Jackson, a parent responding to criticisms of cell therapy, wrote:

> We believe that in a democratic society parents should be permitted to make decisions that affect the upbringing of our children so long as we don't put the children at risk or disadvantage, and being able to make those decisions is a **right**, not a privilege which can be withdrawn at will. (1983, p. 39)

On the other hand, persons who advocate, encourage or permit a particular form of treatment may be regarded as having a professional, moral and/or legal responsibility to ensure that the treatment is effective and safe, and that it does not waste community resources. It is possible for parents and professionals to reach opposing conclusions, each seen as being in the best interests of the child. The purpose of the present review is to examine the effectiveness of less common or non-orthodox attempts which have been made to treat Down syndrome, and the factors which lead some parents to seek controversial and expensive alternative forms of treatment.

NON-ORTHODOX, CONTROVERSIAL AND LESS COMMON TREATMENTS

Among the approaches to the treatment of Down syndrome which have not been fully accepted among professionals are the Doman program, orthomolecular/megavitamin therapy and cell therapy. Facial plastic surgery is practised within orthodox medicine and, although it cannot be defined as an alternative procedure, it is sometimes questioned both on philosophical grounds and because the effect of surgery on speech and behaviour are not yet proven (Dodd & Leahy, 1984; Pueschel, 1984). A frequent criticism of the first three procedures is that there is no properly controlled evidence of their efficacy (Share, 1976; Pueschel, 1981; American Academy of Pediatrics, 1981, 1982).

The accepted procedure for evaluation in medicine is the use of randomised controlled trials. Supporters of the non-orthodox treatments are sometimes critical of this procedure. Hoffer (1972, 1976), who recommends orthomolecular/megavitamin therapy as treatment for a variety of conditions, has criticised the rationale on which controlled trials are based. In a controlled trial, treatments are randomly assigned and are double-blind: that is, neither the patient nor the doctor knows who is receiving which treatment. Hoffer argues that, particularly with psychiatric illness, the faith of the patient in the doctor, and of the doctor in the treatment, are important parts of therapy which are eliminated in double-blind studies.

Some supporters of non-orthodox procedures believe that their research is treated differently from that of orthodox practitioners. Rimland (1982, 1983) asserts that because megavitamin therapy is not supported by established medical authorities, well designed studies with positive results are subject to what he regards as unjustified criticism (American Academy of Pediatrics, 1981), while negative reports are readily published (Smith, Spiker, Peterson, Cicchetti & Justice, 1983). Doman defends the lack of research into his methods by arguing that the work of treating handicapped children is too important to be constrained by the demands of controlled research:

> A clinic is about as far removed from the theoretical, neatly ordered, contemplative, disembodied sort of laboratory research as one can imagine . . . One cannot lock the door at five o'clock on desperately needful children . . . Face to face with a child who may be paralysed, often gasping for breath . . . and always hurt, hurt, hurt, there is little opportunity for scholarly contemplation. (1974, p.107)

Doman consequently relies on clinical observations as evidence for the success of his treatment program. He argues that parents, physicians and professionals cannot wait for years to find 'scientifically immaculate' results of controlled trials (p.257). Doman's arguments, justifiably regarded by professionals as emotive and unscientific, may nevertheless be found by some parents to be convincing.

Clinical observations are also used by Schmid (1978a; 1978b; 1978c; 1981; 1982) in support of the controversial procedure of cell therapy. Schmid asserts that the necessary documentation and case control is provided by the results of treatment of large numbers of children over a long period and that its validity is secured by its practical success. Some of Schmid's reports have used large samples of treated and untreated children with Down syndrome (1978a; 1981). Other findings, however, are descriptive and are presented without supporting evidence (eg. 1978a, p.30; 1981, p.195).

In view of the criticisms, it is interesting to consider the basis, scientific and otherwise, for the non-orthodox and less accepted treatment programs.

EVALUATION OF TREATMENTS[1]

Vitamin and mineral therapy

While vitamin therapy has been shown to produce clinically significant changes in certain disabilities involving inborn errors of metabolism (Hillman, 1976; Scriver, 1973), it is less certain that such changes are possible in Down syndrome. The theoretical argument for vitamin therapy would be supported if it were possible to demonstrate that the vitamin status of persons with Down syndrome is different from that of other persons. In an early study, Gershoff, Hegsted and Trulson (1958) compared the metabolism of water-soluble vitamins in groups of intellectually handicapped children, with and without Down syndrome. Insignificant differences were observed between the groups in the excretion of vitamins. Skin thickening and dryness (hyperkeratosis) has been suggested as clinical evidence of vitamin deficiency in Down syndrome. Matin, Sylvester, Edwards and Dickerson (1981) studied the vitamin and zinc status of three groups of intellectually handicapped subjects: persons with Down syndrome and hyperkeratosis; persons with Down syndrome without hyperkeratosis; and persons with neither Down syndrome nor hyperkeratosis. No significant difference in vitamin or zinc status was found among the groups. Low values for vitamins A and B, thiamine, nicotinic acid and ascorbic acid were found, but these applied equally to the three groups.

The possibility of using megavitamin therapy as treatment for various forms of intellectual handicap, including Down syndrome, received a stimulus from the publication of the results of a study by Harrell, Capp, Davis, Peerless and Ravitz (1981). Harrell's rationale for treatment was based on a single case study in which it was asserted that a severely retarded seven-year-old boy became normal by age nine, following administration of nutritional supplements. Her hypothesis was that retardation is a genetotrophic disease in which the patient has a genetic pattern which requires treatment through an augmented supply of specific nutrients (Williams, 1956). From an initial sample of 22 children, 15 were given nutritional supplements consisting of 11 vitamins and eight minerals over an eight-month period. For the first four months, 10 of the children received placebos, while the remaining 5 received the supplements (the imbalance in groups was caused by an uneven dropout rate). For the second four months, all children received supplements. Group status was not known by the investigators.

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[1] This section is based on Foreman P. & Ward J. (1987). Treatment approaches in Down Syndrome: a review. *Australia and New Zealand Journal of Developmental Disabilities*, 12, 2, 111-121.

After the initial four months, IQs of children in the experimental group were reported to have risen by significantly more than those of the control group children, who showed significant gains in IQ during the second four month period, when they were receiving nutritional supplements. During supplementation periods, IQ changes ranged from a drop of 1.5 points to an increase of 25 points while, during the placebo period, changes ranged from a drop of 7 points to an increase of 4 points. Changes were also reported in height and visual acuity. However, only four of the 15 subjects had Down syndrome. Three of these children were reported to have made IQ gains of 10 to 25 points during the study and to have changed notably in physical appearance through the loss of 'accumulated fluid in their faces and extremities' (p.577). Two children with Down syndrome ceased wearing glasses after their eyesight improved. Interest in the results reported by Harrell et al led the American Academy of Pediatrics to issue a policy statement criticising the study on its methodology and conclusions (1981). It also questioned the basic premise that intellectual handicaps arising from such diverse aetiologies as trauma, infection and chromosomal abnormality could be expected to respond to one form of treatment.

Follow-up studies using vitamin and mineral supplementation have not supported Harrell's findings. Weathers (1983) conducted a double-blind study of 47 children with Down syndrome who were given megadoses of multi-vitamin supplementation over a four-month period, and found no difference between treated and untreated groups in measures of vision, IQ and visual-motor integration. Bennett, McClelland, Kriegsmann, Andrus and Sells (1983) used double-blind procedures and found no significant treatment effects in ten children treated with high-dosage vitamins and minerals over an eight-month period, when compared with untreated children. Another double-blind trial, described by its authors as the Chicago study, followed 56 children with Down syndrome for eight months and reported identical developmental patterns for treated and untreated groups (Smith et al., 1983; Smith, 1984; Rolland & Spiker, 1985). Studies with adults have also failed to produce significant effects (Ellis & Tomporowski, 1983; Ellman, Silverstein, Zingarelli, Schafer & Silverstein, 1984).

Supporters of orthomolecular medicine advocate the use of megavitamins as treatment for a variety of disabilities in addition to Down syndrome. Orthomolecular medicine is defined by Reading (1979) as:

> the study of genetic, metabolic, endocrine, immunological and toxic disturbances that are contributing to, perpetuating, exacerbating, or even causing the psychiatric symptomatology. (p.40)

Orthomolecular medicine has used large doses of vitamins and minerals as an alternative approach in the treatment of schizophrenia (Hoffer, 1973), infantile autism and other disorders (Rimland, Callaway & Dreyfus, 1978). The effectiveness of the procedures was questioned by a task force of the American Psychiatric Association (1973) and remains controversial (Wolliscroft, 1983). Turkel (1963, 1975), a consistent proponent of an orthomolecular approach, has been treating Down syndrome with his 'U' series drugs since the 1940s. The 'U' series (a mixture of 48 vitamins, minerals, enzymes and other drugs) was reported by Turkel (1963; 1975) to have the effect in Down syndrome of 'diminishing inborn structural, functional and chemical abnormalities' (1963, p.409). To support his methods, Turkel presented photographic evidence, but controlled studies were not reported. Bumbalo, Morelewicz and Berens (1964) conducted a double-blind study of the 'U' series of drugs with the co-operation of Turkel, who supplied the treatment and placebos. The study lasted for one year and involved 24 children, 12 treated and 12 untreated. The report by Bumbalo et al contained limited data, but the conclusion that there was no observed improvement in the twelve treated children has been used since as the primary evidence against the 'U' series of drugs. Rimland (1983) criticised the Bumbalo study and the tendency for medical authorities to accept poorly documented studies with negative findings but to be critical of studies which produce positive findings, Turkel, while continuing to provide his drug ltreatment in the United States, has not published further results of controlled investigations of its effectiveness in Down syndrome.

A potential complicating factor in the use of vitamins is evidence that megadoses of vitamins can have toxic side-effects. Schaumberg et al (1983) presented seven case reports indicating severe sensory neuropathy in association with megadoses of pyridoxine (Vitamin B6), a water-soluble vitamin previously thought to present little problem. A possible source of toxicity in vitamin megadoses is impurity in the pharmaceutical product (Rudman & Williams, 1983). The American Food and Drug Administration requires synthetic vitamins to be 98 percent pure. Tests for safety are with normal physiologic doses. The prescription of doses of 2,000 times the recommended daily allowance means that a toxicity level of up to 2 per cent is also multiplied by this amount. Adverse side effects have also been reported from vitamin treatments using normal dosages (Hellriegel & Reuter, 1980). Podell suggests that failure to study seriously programs involving vitamin therapy may result in overlooking both useful therapies and important toxicities (1985, p.116).

Cell Therapy

Cell therapy involves the injection of freeze-dried organ cells (siccacells) from foetal lambs, on the theoretical basis that the cells will be absorbed by corresponding malfunctioning organs with consequent improvement of organ function. Most work on the application of cell therapy in Down syndrome is being done in Germany by Schmid (1976; 1978a; 1978b; 1978c; 1981; 1982; 1984), who does not use cell therapy in isolation, but also prescribes vitamins, minerals, enzyme therapy, endocrine substitution and improved diet, as well as educational, psychological and paramedical treatments. Schmid refers to the total treatment as 'holistic medical therapy' (1981, p.184) and it would be difficult to attribute successful outcomes to a particular aspect of the therapy regimen. Demonstration of significant effects could be used as evidence of the efficacy of the total treatment program, and may lead to isolation of aspects of the program producing beneficial results.

As evidence of the effects of holistic medical therapy on height, weight, head circumference, cranial volume and various measures of general development, physical comparisons were made by Schmid between a total of up to 1,546 treated and untreated boys and between 1,190 treated and untreated girls (1978a; 1981) (precise numbers of children in experimental and control groups were not provided, nor is there information about how the groups were selected). According to Schmid, girls with Down syndrome who commenced treatment before the age of eight reached an average height at maturity which was 10cm greater than that of untreated girls. In boys, the difference was 13cm (1981, p.187). Weight development was 'largely compatible with . . . height' and there was 'no statistically detectable overweight' (1981, p.192). Head circumference of boys at age 17/18 was, on average, 0.7cm larger than untreated boys and 1.5cm smaller than normal boys. For girls, the corresponding figures were 1.1cm and 2.4 (p.192). The three-dimensional cranial volume index used by Schmid is based on X-ray measurements of the three largest diameters of the neurocranium compared with the surface measurement of the fronto-occipital circumference of the skull. Schmid (1981) presents cranial volume index figures for 12 boys and 12 girls treated before the age of two, and for 12 boys and 12 girls whose treatment commenced after the age of two. Results are presented as graphs. Means or ranges are not reported, nor are there statistical comparisons. Graphs for boys indicate indices falling within the low normal range. For both boys and girls, early treatment produced higher cranial indices than late treatment. Schmid suggests that increased cranial measurements are associated with more normal facial appearance in children with Down syndrome:

> The closer the brain volume (size of the neurocranium) approaches the normal values, the less pronounced become symptoms such as obliquity of the axis of the eyelids, button nose, saddle nose and broad, flat face. (1981, p.193)

There have been several attempts to evaluate the effects of cell therapy. Such studies are difficult methodologically because of the need to allow time for predicted developmental changes to occur and because of the difficulty of obtaining random assignment to experimental and control groups. Goldstein (1961) treated 100 intellectually handicapped children, of whom 35 had Down syndrome. The treatment period averaged two years and variables measured included intelligence, speech, gross motor, attention span and physical growth. Although only limited data were presented, results were reported to show relatively greater improvement for the cell therapy group on all measures. However, evidence of negative results have also been reported. A small double-blind trial producing negative results was reported by Bardon (1964) and similar results were reported by Black, Kato and Walker (1966). White reported negative findings in a study of West German and American children receiving combined vitamin/mineral and cell therapy (1969), while Berry and Gunn (1983) reported a small study which found no evidence of atypical increases in mental or motor age in six children receiving cell therapy. A recent Australian study of 23 treated children and 23 controls also found the procedure to be ineffective (Foreman & Ward, 1987).

Doman Program

The theoretical basis of the Doman program is that there are four essential stages of human brain development, corresponding to the sequence of phylogenetic development. The brain of each creature on the evolutionary scale contains abilities needed for survival, together with those abilities needed by creatures lower on the scale. It is argued that in a child with brain injury, the inherited reflexes will not be felt, and it is necessary to use external means to impose the basic movement pattern on the child. The type of movement pattern imposed, dependent on the level of brain development at which damage is believed to have occurred, is assessed using a developmental profile (Institutes for the Achievement of Human Potential, 1965).

Delacato (1959; 1963; 1966) and Doman (1974) developed the procedures currently used in the Doman program. While Delacato's interest was in disabilities in reading and learning, Doman extended this to general development and, in particular, to treatment of brain injury, which, for Doman, includes brain damage, mental retardation, mental deficiency, cerebral palsy, emotional disturbance, spasticity, flaccidity, rigidity, epilepsy, autism, athetosis and hyperactivity (1974, p.220). Down syndrome is also treated. Programs provided through the Institutes for the Achievement of Human Potential have been well-supported by parents but have been subject to considerable criticism from education and health professionals. The American Academy of Pediatrics (1982, p.810) has summarised the main areas of concern in terms of:

1. Promotional methods which make it difficult for parents to refuse treatment.
2. Demanding, inflexible and stressful treatment procedures.
3. Assertion that failures are attributable to inadequate effort by caregivers.
4. Restrictions on age-appropriate activities of which the child is capable.
5. Use of an unvalidated developmental profile.
6. Unsubstantiated claims of dramatic improvements and cures.

In Australia, the National Health and Medical Research Council (1976) acknowledged positive aspects of the Doman-Delacato program, but criticised the absence of demonstrated effects and the lack of a scientific basis for the procedures.

The limited amount of controlled research into the effects of the Doman program has not supported the use of the procedures in preference to more conventional treatments. In an early study, Doman, Spitz, Zucman, Delacato and Doman (1960) reported marked improvements in mobility among 76 brain-injured children treated through patterning and sensory stimulation. In a later study of three groups of severely intellectually handicapped, institutionalised children (Sparrow & Zigler, 1978), one group followed Doman's patterning program, the second was given a motivational program and the third received normal care. No significant treatment effect was found for the Doman program. Similarly, a controlled study by Fredericks (1969) found that groups of children with Down syndrome following a behavioural program aimed at improving their motor ability showed more gains over a 9 week period than groups of children following a program based on Doman-Delacato methods. However, the intervention period in Fredericks' study was brief and it may be that more time is needed in studies looking for developmental changes.

Information provided by Doman tends to be subjective and descriptive and to promise dramatic improvement:

> There are many hundreds of brain-injured children two, three and four years old, who can read with total understanding from a few words for some to many, many books for others. I know a few three-year-olds who can read in several languages with complete understanding. (Doman, 1974, p.185).

Such claims are a marked contrast to conventional professional prognoses and are consequently attractive to some parents. The conclusion reached by the American Academy of Pediatrics, following its study of the work of Doman, Delacato, and the Institutes for the Achievement of Human Potential was that the treatment had no special merit, its claims were unproven, and the demands on families were so great that harm could result from its use (1982, p.811)

Facial plastic surgery

Facial plastic surgery in Down syndrome is a relatively recent procedure and involves surgical treatments including tongue reduction, lower lip reduction, chin implants, nasal implants, correction of the oblique inclination of the eyes, and removal of fat tissue from the anterior neck area (Hohler, 1977; Lemperle & Radu, 1980; Lanigan, 1985). A recent computerised anthropometric investigation of abnormal facial measurements and proportions in Down syndrome found that the most striking facial differences in persons with the syndrome were the inclination and shortness of the palpebral fissures, although the tongue size was also recognised as a problem (Farkas, Munro & Kolar, 1985). Not all surgical procedures are used with all children, tongue reduction being performed most frequently. For example, in Lemperle and Radu's series of 67 children, 63 received tongue reductions while only 8 had the inclination of their eyes corrected (1980, p.339).

There are two primary goals in facial plastic surgery: to make the child's physical appearance more normal; and to improve the child's general functioning. Plastic surgery has a proven ability to produce changes in facial appearance. Procedures now used in Down syndrome are ones that have been documented in other persons with facial anomalies. Photographs provided by Olbrisch (1982), Wexler and Peled (1983) and Lemperle (1985) offer evidence that marked changes in physical appearance are possible. Changes in function are more difficult to substantiate.

It is well established that children with Down syndrome have problems related to tongue movement and feeding (Gisel, Lange & Niman, 1984). Tongue reduction has been reported to lead to more normal mouth closure, fewer respiratory tract infections, decreased mouth-breathing, better eating and improved speech (Olbrisch, 1982; Rozner, 1983, 1984). Lemperle (1985) reports a series of 107 tongue reductions following which 68 percent of parents reported improved speech, 20 percent reported no change, and 7 percent said that speech was worse. There remains some doubt about the extent to which persons with Down syndrome have tongues which are excessively large (Ardran, Harker & Kemp, 1973). There is also doubt about whether possession of a large tongue is the cause of speech and respiratory difficulties. For example, it is possible that speech difficulties in Down syndrome result from a central motor deficit leading to generalised hypotonia, rather than from a peripheral disorder of articulation (Dodd & Leahy, 1984). A recent study by Parsons, Iacono and Rozner (1987) examined changes in articulation in 18 children with Down syndrome immediately following tongue reduction surgery, and at follow-up six months later. No significant lessening of articulation errors was observed. Further controlled studies of the effects of surgical techniques on speech are necessary.

Even though it is acknowledged that surgery can be successful in altering appearance and tongue size, there is controversy about whether plastic surgery is indicated in Down syndrome. Pueschel (1984) argues that such surgery is required only if the child has a significant deformity. He challenges the view that the physical characteristics of Down syndrome are deformities. A survey by Pueschel of the perceptions of parents and physicians indicated that parents were much less likely than physicians to regard facial features of Down syndrome negatively. Mearig (1986) analyses facial surgery in terms of Feuerstein's concept of active modification and concludes that it is necessary for parents to be given enough information to be able to see what options are appropriate for their child. Risk and pain factors must also be considered.

Questions remain about other aspects of facial plastic surgery in Down syndrome. An important question concerns the social effects of changes in facial appearance. It is likely, for example, that a person whose appearance is close to normal will be treated differently from a person who has obvious facial differences, and that this may lead to more normal functioning in the person. On the other hand, it is possible that a person with relatively normal appearance but with abnormal speech and limitations to intellectual functioning may find relationships more difficult to establish than a person whose appearance explains abnormal aspects of his behaviour. Whether facial plastic surgery leads to behavioural or cognitive changes in Down syndrome is a significant research question which remains to be answered (Dodd & Leahy, 1984; Lemperle, 1985).

THE STATUS OF ALTERNATIVE MEDICINE

By definition, alternative medicine is outside and alternative to orthodox or conventional medical practice. If it is accepted as standard procedure, it is no longer alternative medicine. Maddocks (1985) described alternative practice as an embarrassment to modern medicine, suggesting that doctors are confused about whether to reject it, ignore it, or use it more often. Important questions to be answered concern how orthodox and alternative medicine relate to each other, and why some persons seek treatment through alternative medicine instead of, or in addition to, orthodox procedures. Maddocks suggests that there is a need to obtain information about who uses the alternative techniques, why they have taken them up, and what part they play in the therapeutic exchange.

Alternative medicine appears to be well accepted by consumers, involving perhaps 8 percent of professional consultations (Wiesner, 1983). A study of 238 Australian families by Donnelly, Spykerboer and Thong (1985) provides evidence that consultation of alternative practitioners is quite common and that patients do not choose alternative medicine because they are unhappy with orthodox medicine. The sample comprised the families of 128 asthma sufferers and 110 children hospitalised for minor surgery. Nearly half of each group had consulted alternative practitioners, but fewer than 10 percent of each group stated that they were dissatisfied with orthodox medicine.

In a small descriptive study, Poole and Anstett (1983) questioned patients in a general practice about their reasons for seeking alternative health care. They found that there were three reasons why patients sought alternative treatment: desire for a natural approach; religious, familial or cultural traditions; and frustration with orthodox medicine. In most cases the physician and patient were able to negotiate a compromise, such as a monitored trial of the alternative treatment. Freer (1985) suggests that it is preferable for some alternative procedures to be used within the context of the primary health care team than for the important doctor/patient relationship to be impaired.

Reilly (1983) surveyed 86 general practitioner trainees about their knowledge of, attitude to, and use of alternative procedures. He found evidence of increasing acceptance of alternative medicine. One third of the doctors had referred the patients for alternative therapies, and one quarter had been treated themselves by alternative procedures. Reilly's research produced warnings by Smith (1983a) about the need for doctors to recommend only treatments which had been scientifically validated. However, while he suggested that doctors should be able to tell patients which treatments have been evaluated, he cautioned that they should not denigrate the benefits coming from a caring therapist and a believed-in treatment. In his response to Reilly's research, Smith (1983b) argued that patients need to recognise the fallibility of both orthodox and alternative practitioners.

An important concept in the study of the effects of alternative medicine is what Tonkin refers to as self-healing (1982. p.814). This may range from spontaneous recovery to self-control of body metabolism, and includes placebo effects of drugs and other procedures. Tonkin suggests that excessive dependence on both orthodox and alternative medicine may result from the failure of patients to recognise their own self-healing ability and from the notion that recovery from illness is always the result of action by an outside agency. It follows that some of the success of alternative medicine, like that of orthodox medicine, results from activation of the patient's self-healing capacity. Like Smith (1983b), Tonkin advocates acceptance by patients of greater responsibility for their own health.

Why do Parents Choose Alternative Therapies?

It is reasonable to suggest that alternative therapies are most likely to appeal to persons for whom orthodox medicine is unable to provide treatment. This includes persons with terminal illnesses, people with chronic conditions which do not respond to orthodox treatment, and parents of children with untreatable disabilities. Orthodox practitioners are frequently in the position of having to point out that, on the basis of current scientific knowledge, no treatment is possible. Alternative practitioners may not be similarly constrained. The alternative treatment offered is likely to be satisfying to the client, either as a result of a genuine improvement, or because of the physical and social milieu in which the treatment occurs, and the resultant self-healing or placebo effect.

In a recent study, parents of 43 children with Down syndrome were asked about their use of less common treatments, other than cell therapy. (The parents had been selected on the basis that their children weren't receiving cell therapy). Thirty-five percent of the parents were using or intended to use a less common treatment, cosmetic surgery being the most popular. In addition it appears that at least 150 children in Australia are receiving cell therapy even though it is unproven and may have side-effects. It could be hypothesised that parents who are faced with the knowledge that their child has a disability which is associated with major physical, intellectual and social limitations, will expect some form of medical treatment. Such treatment is unlikely to be offered unless the child has an associated medical disability (Foreman & Ward, 1986). Following the arguments of Tonkin (1982) and Maddocks (1985), it is understandable that many parents of children with Down syndrome feel the need for their child to receive medical treatment directed at symptoms. On current knowledge, such treatment is unavailable (Lejeune et al, 1983).

It would be simple to explain parental interest in alternative therapies in terms of guilt or anger about their child's disability. Cunningham and Glenn (1985) warn against using a pathological framework to interpret parental behaviour. The explanation for the parental search for alternatives may, indeed, be both in the nature of the limited conventional services available and in the contrast between these and the alternative therapies. The fact that a treatment exists will mean that some people are likely to use it, particularly if it has received media publicity. Professionals should not be surprised if parents do not share their approach to evaluation of the likely effect of a procedure. Most parents have greater access to the mass media than to the scientific journals, and have much more to gain than professionals from the potential effect of a treatment. Professionals who caution against a treatment are working within the scientific framework in which they have been trained. Parents who accept such advice lose the theoretical possibility that their child's problem may be alleviated.

A feature of the conventional therapies is the slow and undramatic nature of their effects. The highest quality physiotherapy, occupational therapy, speech therapy and early intervention programs will produce results which occur slowly. Children's progress as a result of such programs may be seen as little different from expected developmental progress. Drug-based therapy, by contrast, suggests the possibility of quick and far-reaching change. Other, alternative, therapies, unconstrained by a belief in scientific documentation, may promise substantial change in a condition which orthodox medicine says is fixed.

The question arises of whether orthodox paediatric medicine provides an adequate service to persons with Down syndrome. An adequate service would need to be perceived as such both by practitioners and by parents. In an English study, Murdoch (1984) found that only 12 percent of children with Down syndrome were referred to paediatrians by general practitioners. A recent Australian study suggested that about 50 percent of children with Down syndrome cease being seen by a paediatrician by age 11, and over 65 percent by age 15 (Foreman & Ward, 1986). Post-adolescent care would be primarily by general practitioners. Even when such children are under medical care, good conservative practice would suggest that, in the absence of other illnesses, pharmacological therapy and prolonged specialist management is unnecessary. This conclusion may conflict with parental perceptions about treatment of serious disability, and may motivate the search for alternative therapies.

Because of the relative rarity of Down syndrome, it could not be expected that all paediatricians or general practitioners would be in frequent contact with the condition and there is evidence that some paediatricians are not familiar with normally expected developmental progress in the syndrome (Foreman & Ward, 1986). The question arises of whether the condition is sufficiently specialised to suggest the need for clinics either specifically for Down syndrome, or for Down syndrome and other developmental disabilities. In the United States, Fujimoto, Fareau, Forsman and Wilson (1978) reported the operation of a sub-specialty clinic specifically for Down syndrome. They found that children attending the clinic needed less hospitalisation than those not provided with such a service. Beange (1986) recently reported the presence of multiple undetected and untreated physical impairments in a population of 165 intellectually disabled adults. The creation of a specialty in the lifespan treatment of developmental disabilities could fill a gap in current services.

It is easy to attempt to explain the parental search for alternative therapies in terms of a need to overcome guilt or anger associated with their child's handicap. Such explanations ar over-simplistic and ignore the complexity of a situation which includes at least an interaction between parental expectations, societal expectations, the condition of the child and the quality of available therapeutic services. When optimum quality service is offered to each family on the birth of a child with a disability, and throughout life, there may be fewer who feel the need to seek alternative therapies. Even so, there will be some parents who will find the conventional offerings do not meet their expectations and will pursue their right to seek alternatives.

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Chapter 32

EVALUATING EARLY INTERVENTION PROGRAMS: METHODOLOGICAL CASE STUDY

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ISSUES IN PROGRAM EVALUATION

During the decade from 1975 to 1985 there has been a growing recognition in Australia of the importance of early educational intervention for young handicapped children and a corresponding growth in the provision of programs. The Schonell Educational Research Centre survey of early intervention programs during the middle of the decade found that more than 130 had been established in Australia (Fred and Eleanor Schonell Educational Research Centre, 1982). By 1985, many more programs were funded as a result of the increasingly important role that early intervention was perceived to fulfil. Immense diversity characterised the programs included in the Schonell Centre survey. The number of children served varied from 4 to 427. The type of service consisted of home, centre, or hospital based intervention or a combination of these. The staff employed varied from medically-oriented therapists to teachers. The level of staff qualifications varied from unqualified to postgraduate. The intensity of the program varied from a weekly or fortnightly consultation or therapy session to daily group and/or individual work. The source of program funds and the type of management structure also varied considerably. Of the forty or so programs in New South Wales five were under the auspices of a tertiary institution, about half the remainder were administered directly or indirectly by government departments, and the rest were funded by private or voluntary agencies.

Despite a general acceptance of the value of some form of early intervention for at-risk children the diversity of programs reflected widely differing views as to what constituted early intervention. The report of the Schonell Educational Centre Survey (1982) argued that in the light of the great program diversity there was a need to establish the educational effectiveness of programs in the Australian context. Irvine and Wilton (1978) had also identified a need for Australian educators to report on the impact of early intervention programs. The example of a small number of university-based research projects such as the Macquarie Down syndrome program (Pieterse, 1978; Pieterse, Cairns, & Treloar, 1980; Pieterse & Center, 1984; Pieterse & Treloar, 1981) and the work of Clunies-Ross (Clunies-Ross, 1979, 1981) in the rigorous documentation of program impact and the development of curriculum materials has not been followed by programs whose focus has been direct service delivery. One of the most striking features of the present pattern of early intervention services is the lack of substantial evaluation of the various program models that have been developed for Australian children.

The purpose of the present chapter is (a) to identify the rationale for evaluating Australian programs such as the Liverpool Early Education Project (LEEP) for young severely handicapped children funded by the Commonwealth Schools Commission Severely Handicapped Children's Program, (b) to examine factors that influenced how the evaluation was conducted, and (c) to describe the evaluation strategy adopted reflecting those influences. The final section of the chapter draws some major conclusions about evaluating early intervention programs.

RATIONALE FOR EVALUATING THE LIVERPOOL EARLY EDUCATION PROJECT

There are at least four compelling reasons for more widespread evaluation of early educational programs for young handicapped children. First, there is a need for a more rigorous documention of the effectiveness (both short- and long-term) of early educational intervention for developmentally delayed children in the Australian context particularly if there is debate about the effectiveness of a teacher's contribution to such programs. Secondly, the relative effectiveness of different models of service delivery and different approaches to curriculum construction need to be further examined in order to develop more effective programs on the basis of data and experience rather than merely to repeat the mistakes of the past. Thirdly, since the intensive nature of the service leads to high costs there is a need to examine the relative costs of different forms of service delivery so as to make the best use of the scarce resources that are available. Fourthly, there is the need to encourage improvement of existing direct service delivery programs by providing feedback to funding committees management, and staff about the processes and outcomes of their efforts. Takanishi (1979) has suggested that the most important characteristic of an evaluation is its utility or the extent to which it leads to program improvement and the development of children's skills.

In spite of the compelling arguments to support program evaluation and the practicability of doing so, the most outstanding single characteristic of the current Australian situation in intervention programs is the dearth of evaluation efforts of direct service delivery programs. There are a number of possible reasons for the failure to undertake program evaluation. One important reason lies in the frequent failure on the part of both program management and staff to appreciate the need for evaluation particularly where the primary focus has been on providing a direct service to the children and their families. There is also the lack of expertise, staff, and available time in most service-oriented programs to devote to evaluation. Another area which makes evaluation more difficult is the imprecise formulation of program goals and policy statements. The absence of precise records of child progress makes the task of demonstrating program impact a daunting one. As well, the evolving nature of many programs during the first few years of functioning limits the form an evaluation can take. Many Australian programs are still in an early stage of development and are thus undergoing change as they move towards their ideal method of service delivery. Finally, the failure of funding committees to provide clear guidelines for evaluating programs or indeed to provide funds for the purpose serves to reinforce the impression that evaluation matters little. Generally the only requirement is one of minimum financial accountability. External evaluation may not always be possible if program management or the funding committee do not provide the funds.

However, it is possible in spite of the problems to evaluate early intervention programs. One program that has been evaluated recently is the Liverpool Early Education Project (LEEP) the first major early intervention program funded in New South Wales by the Commonwealth Schools Commission Severely Handicapped Children's Program. Two factors were important in the planning of the evaluation (a) the nature of the goals of the program that was funded and (b) the function that the evaluation was intended to serve in that context.

The Program and its Context

The LEEP program was funded in 1983 as a pilot program with its purpose defined as being to:

1. Establish a model of home-based educational intervention for young severely handicapped children.
2. Evaluate the procedures, curriculum, and strategies used.
3. Provide for replication by other personnel in other settings.
4. Complement the already existing range of services provided by private and government agencies in the Liverpool Region of the New South Wales Department of Education.

LEEP was designed to assist families with the problems and issues arising from daily involvement with a young severely handicapped child by either directly working with the child's parents and/or by referral to another agency. The emphasis was on meeting individual family needs based on the rationale that with such help a family would become more comfortable and confident and thus be better able to meet the child's educational needs. A home-based service involved visiting homes, observing children, and working with the parent and child in the home environment. Subsequently a centre-based service provided an educational environment which facilitated the development of social skills, encouraged generalisation of previously learned skills, and developed new skills. Teaching staff sought to identify a child's developmental, functional, and behavioural needs and to address the needs in the context of the family environment. The therapy services integral to an educational program were to be provided as needed by other agencies.

Challenge Foundation of New South Wales (a voluntary agency providing services for the intellectually handicapped) and the Liverpool Region of the New South Wales Department of Education (the State education authority providing regular and special education) had prepared the successful joint submission to establish LEEP. A management committee was established representing both organisations with responsibility for the day to day operation of the program. An advisory board was also appointed as a means of facilitating coordination with other services in the region, drawing on the available local knowledge, and providing a source of outside expertise. Subsequently, a regional inter-agency committee was formed to provide a means for consultation between the different early childhood special education services.

The Purpose of Evaluating LEEP

Despite lack of initial specific funding for evaluation, the Advisory Board during 1984 appointed an evaluation sub-committee from its members. The decision reflected a commitment to evaluation by the Board members, program management, and staff. On commissioning the evaluation the LEEP Advisory Board defined two objectives. The first was to analyse LEEP in terms of the aims and purposes of the funding submission and the way the goals for the program had been implemented. The second was to reach some tentative conclusions about present program effectiveness and to suggest guidelines for the future development of LEEP. Further evidence of a commitment to evaluation came when the Board appointed an external evaluator to supplement the internal evaluation at a stage when some funds were made available. One of the reasons for evaluating LEEP reflected the initial concept of a program with a research and curriculum development component. The requirement of the funding committee to evaluate the procedures, curriculum, and teaching strategies reflected the interest in program effectiveness as basis for future funding applications.

The main purpose of the LEEP evaluation, then, was to assess the pilot program after one year of operation in order to provide a basis for decision making about the future of the program. The concept of evaluation as a basis for decision making underlies much of the literature in the field. Cronbach (1980), Patton (1978), Stake (1976), Stufflebeam (1972), Stufflebeam, Foley, Gephart, Guba, Hammond, Merriman, and Provus (1971), and Weiss (1972) defined the function of program evaluation as being to provide information which will help reduce the uncertainty under which organisational decisions are made. Anderson and Ball (1978) made a useful distinction between three kinds of decisions that program evaluation can contribute to. First, decisions about program installation are about needs assessment, the demand for the program, the conceptual adequacy of the curriculum, staff accountability, and resource requirements. Secondly, decisions about program continuation are about expansion, contraction, and certification of the service and generally relate to externally conducted summative evaluation. Thirdly, decisions about program modification are about the service delivery system, program content and implementation, staff competencies, and inservice training. Such an evaluation may be internally conducted and formative in nature. The evaluation thus sought to highlight the strengths and achievements of LEEP during its first year of operation and the nature of the inevitable problems resulting from establishing a new service.

Factors Influencing the LEEP Evaluation

The process of the LEEP evaluation provides a useful case study illustrating the relationship between the context of the evaluation, the questions asked, and the evaluation strategy adopted. There were a number of factors that needed to be considered in designing the evaluation. In particular, Ferguson (1983) had identified the information needs of the various decision makers and the political, financial, ethical, and physical constraints of the specific program situation. The methodology needed to be able to reflect the intention of the Advisory Board in calling for an evaluation and to cater for the range of potentially conflicting purposes (both explicit and implicit) of the various interest groups represented on the Board. The evaluation design therefore needed to take into account (a) the interests of the relevant decision makers, (b) the questions being asked, (c) the constraints on the evaluation, and (d) development of a focus for the evaluation.

The Interests of the Relevant Decision Makers

The first step was to identify all relevant decision makers who were actively interested in the evaluation and therefore likely to make use of its findings (Patton, 1978). For most early intervention programs there are at least four main groups of decision makers: funding committees, management committees or program coordinators responsible for management and policy development, direct service providers such as teachers or therapists, and the families of children in the program.

There were a number of significant stakeholders in LEEP representing diverse and potentially conflicting interests. At the funding committee level there were the New South Wales Working Committee of the Severely Handicapped Children's Program on whose decisions continued funding largely depended and the Commonwealth Schools Commission who provided the funds. Both would be concerned with evidence as to program effectiveness. At the level of the management committee representing the two sponsoring organisations there were different perceptions about what LEEP was supposed to be doing. The New South Wales Department of Education viewed LEEP as a model for future initiatives in early childhood special education while Challenge was seeking to provide for a group of children in the severely handicapped range for whom the current Challenge home-based program seemed to be less than adequate. At the level of policy development the members of the Advisory Board themselves had a variety of expectations of LEEP reflecting the diverse and conflicting interests of the agencies they represented (the New South Wales Department of Education, Challenge Foundation of New South Wales, the New South Wales Department of Health, the New South Wales Department of Youth and Community Services, the New South Wales Council for the Intellectually Handicapped, Macquarie University, the Institute of Early Childhood Studies at Sydney College of Advanced Education, and Cumberland College of Advanced Education). At program staff level there were the teachers who sought confirmation of what they had achieved. At the level of the users of the service, there were parents of children participating in the program who wished to ensure the continued existence of LEEP.

There were therefore a number of audiences for the evaluation each seeking different outcomes and emphases from the findings. The problem for the evaluation has been pointed out by Alkin (1981) who argued that attempts to meet the divergent needs of too many decision makers may simply lead to confusion on the part of the evaluator and concluded that it might be necessary to limit the focus of the evaluation to the needs of a particular person or group of persons with similar needs.

Determining the Questions Being Asked

There were a number of considerations in choosing the relevant questions (Patton, 1978). The first task was to establish priorities for the many and often conflicting questions being asked. The funding committee and the management committee were interested in program outcomes, child progress data, and evidence that the program was in fact implemented in the way the funding submission had proposed. Program staff were interested in the processes of operating the program. The New South Wales Departments of Health and of Youth and Community Services and other local agencies were interested in the degree of coordination with the services already existing in the region. The priority assigned to questions for the evaluation ultimately reflected the interests of the Advisory Board commissioning the investigation since the interests of the identified decision makers were of paramount importance. Other questions could be answered only if they did not conflict with those asked by the Advisory Board. The implicit expectations of the decision makers for the evaluation also needed to be assessed and the most credible forms of data determined.

The second task was to consider the context of the program itself. There was the need to examine the project closely in terms of its history, the physical location, the stage of development, the degree of fluidity, its formal and informal goals, and the availability and accessibility of documentary data. There was the need for some form of assessment of the attitudes of the client parents, the community, and program staff towards both the program itself and the evaluation in order to show up discrepancies in how the program was viewed. It was also important to make an honest appraisal of all political, ethical, financial, and other constraints on the evaluative situation. This involved posing some or all the following questions: To whom would the findings belong? Who else would have access to them? What rights of independent publication would accrue to the evaluator? What would be the likely reaction of various people to unfavourable findings? How would the rights of the families to confidentiality be protected? What were the physical constraints on the evaluator? Would site visits be possible? Would qualitative data be equally or more credible to the particular decision makers concerned? Was there any hostility (obvious or latent) towards the evaluation by any individuals or groups?

Constraints on the Evaluation

There are a number of constraints on the process of documenting the effectiveness of any program for young handicapped children, particularly the severely- or multiply-handicapped. The constraints have been raised by a number of writers in the literature on evaluating early childhood special education programs (Bricker, 1978; May, 1980; Sheehan, 1980; Simeonsson & Weigerink, 1975).

First, the design of an evaluation is constrained by the ethical problems associated with denying a service needed by the children in order to establish a contrast group and the practical problem of finding an appropriate comparison group. Secondly, accurate assessment of child progress is difficult if a child is handicapped. Many standardised cognitive measures are usually not appropriate because they have been normed on a nonhandicapped population. As well, where a program does not specify clear goals and objectives criterion-referenced assessment may prove to be impossible. Thirdly, the effect of severe handicap on either norm- or criterion-referenced measures is not known. Many items are not functional for a severely handicapped population and may make assessment data difficult to interpret in the light of observable divergence between performance on a test item and a child's functional skill level. Fourthly, there is a lack of agreement as to what represents a reasonable rate of progress for young severely handicapped children. It is difficult to determine whether or not any progress made is satisfactory. Fifthly, the direct service nature of many programs means that there is often a lack of time, expertise, or staff to identify, collect, and analyse the data necessary for a comprehensive evaluation. Data crucial to an effective evaluation may not be included in a program's record keeping system making it impossible for the evaluation to utilise data of known validity and reliability. Finally, funding committees generally do not provide guidelines for more than minimum financial accountability of programs nor do they usually provide funds for the purpose of evaluation.

In addition to the more general constraints in evaluating programs for young handicapped children, the unique characteristics and context of LEEP imposed further constraints on the design. The constraints result from the essentially pioneering nature of LEEP as a pilot program in the New South Wales context, the early stage of development of the program at the time of evaluation, and the failure to build an evaluation component into the program from the outset as an integral part of its operation. Each of the factors has influenced profoundly both the form of what was appropriate and possible in the evaluation and the findings and conclusions of the evaluation.

1. **LEEP as a pilot program** broke new ground for every group involved. To each LEEP meant something different and reflected different expectations about the nature of the program. For both sponsoring bodies the joint nature of the project was a departure from usual practice. Challenge staff had already developed skills in delivering a home-based program for moderately intellectually handicapped young children. For Challenge, LEEP was intended as a pilot program to develop an appropriate form of service delivery and an appropriate curriculum for young severely handicapped children. The New South Wales Department of Education was experienced in administering and delivering school-based special education for mildly-to-moderately handicapped children four years of age and over. The Department had provided educational services to children below four years of age only if there were sensory impairments. For the New South Wales Department of Education, LEEP was a new venture in service delivery designed as a pilot for other regions of New South Wales.

For the staff involved, LEEP represented a task that they had not previously undertaken. None of the staff had either specific training or work experience in early childhood education, in home-based early childhood special education, or in collaborating closely with other agencies. The demands of working in LEEP meant learning new skills in working closely with the parents of young severely handicapped children and with staff from other disciplines and from other agencies. In addition, staff needed to become familiar with new teaching methods, curricula, and instructional settings.

For the New South Wales Working Committee for the Commonwealth Schools Commission Severely Handicapped Children's Program, LEEP has also been innovatory. It was one of the first early childhood special education program to receive funding. It was perceived in New South Wales as a pilot program with a research orientation towards curriculum development. In addition, it was a joint project with a private and a government agency as co-sponsors.

In the New South Wales context, there was no existing model for LEEP either in terms of service delivery, curriculum, or management structure. Therefore evaluation criteria could not be derived directly from New South Wales examples of good practice. One source consisted of the program goals described in the joint submission. A second source was the literature concerning the characteristics of effective programs for the young severely handicapped child.

2. **LEEP's early stage of development** had important implications for the nature of the evaluation. Evaluation of programs in an early stage of development is likely to focus on a needs analysis and a monitoring of program implementation with an essentially formative emphasis. Suchman (1972) has characterised the first stage of a pilot program as a pre-evaluation phase where staff are involved in a trial-and-error situation and are testing different structures, methods, and approaches. Because flexibility was important at the early

stage of program development a design which required no significant program changes during the course of the evaluation was of little use. Evaluation of a developed ongoing program can focus more clearly on program effectiveness. Evaluation of a mature program can be based more on a summative assessment of child progress but with some degree of formative assessment in order to provide a breadth of data for program improvement.

At the time of the LEEP evaluation the home-based program had been operating for 11 months and the centre-based program for 6 months. The program was still in a fluid state in developing curriculum, teaching strategies, and data collection methods. As a result, there were insufficient quantitative data over an inadequate time-span to evaluate fully the impact of the program on the children and their families. The focus of the evaluation was therefore largely a formative one with a view to influencing the future directions of the program.

3. **LEEP's lack of an integral evaluation component** meant that data critical for an evaluation was simply not available. The funding submission had proposed an evaluation component in the program and one of the requirements of approval by the funding committee was to evaluate the project. However, no funds were specifically allocated for evaluation and as a result efforts to incorporate an evaluation plan as a program component did not succeed. Consequently, there was no plan to identify the type of internal evaluation data needed or how the data were to be collected. The data collected by program staff were largely qualitative and met teacher needs for planning and recording what the children were doing rather than the needs of program evaluation. The lack of any available pre- and post-intervention measures incorporated as part of the routine teaching procedures proved to be a serious limitation on the evaluation.

Focus of the Evaluation

Writers such as Rossi (1979) and Freeman & Solomon (1981) argue that program evaluation should be comprehensive and encompass all aspects of the program, including a needs analysis, and formative and summative evaluation. A comprehensive evaluation requires planning at the outset of the program. However, it is not possible to complete such an evaluation until sufficient time has elapsed to measure program outcomes. Other writers such as Alkin, Daillak, and White (1979) and Cooley (1983) point out that comprehensive evaluations may be impossible because of the constraints imposed by insufficient resources or the time available for the evaluation. They also point out that a comprehensive evaluation may be undesirable because the wide range of focus questions may lead to role confusion on the part of the evaluator and a failure to meet any one need fully.

Since the Advisory Board who commissioned the evaluation represented a diversity of interests it was important for the evaluation to attempt to address the needs of each of these interests. The result was an evaluation essentially formative in its focus but with an attempt to provide approximations of summative data for the funding committee and the New South Wales Department of Education.

> **A formative focus** seemed to be appropriate in view of LEEP's early stage of development and the largely trial-and-error character of the first year of operation of any program. The relatively short time many of the children had been receiving intervention in either the home- or centre-based program and the lack of quantitative data on child progress proved to be a major limitation of the evaluation of program impact.
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> Some attempt at a **summative evaluation** was nevertheless essential in order to assess program impact and assist decision-making by such stakeholders in LEEP as the funding

committee and the New South Wales Department of Education. The lack of quantitative data on child progress and valid norm-referenced or criterion-referenced measures precluded a definitive statement of program impact. The qualitative data on program effectiveness was obtained from observation of the children, videotapes comparing performance early in the year with later gains, teacher records, parent interviews, and staff from other agencies working with the children.

The Evaluation Strategy

The implementation plan that was developed for the LEEP evaluation needed to take into account both the purpose of the evaluation and the constraints imposed both by the factors specific to the setting and by factors inherent in evaluating programs for the severely handicapped.

Data Collection

Decisions about what information to collect, how to collect it, and how to synthesise and analyse it followed from the decisions about the focus of the evaluation and the detailed questions that arose. If the evaluation effort were primarily to examine the way in which LEEP reflected what the funding submission had proposed and the nature of planning and implementation during the first year of operation there were a number of issues that needed to be considered.

If the emphasis of the evaluation were to be largely summative and concerned with verifying the program's effectiveness in achieving certain outcomes, then more emphasis needed to be placed on collecting quantitative data and providing a sophisticated data analysis. The face validity of the measurement instruments is important in contributing to the credibility of the results supplementing the more traditional concerns of construct validity, external validity, or reliability. If the emphasis were to be largely formative and concerned with describing and understanding how the program operated, then more emphasis needed to be placed on collecting qualitative data, collating them, and teasing out probable answers to the questions asked.

However, both quantitative and qualitative data can be used to complement each other to provide a richer and fuller picture of the program, to examine the processes of the program's operation, and to point to unintended outcomes. Site visits, observations, and interview data would enable more valid and meaningful data to be collected enhancing the quantitative data that might be available (Bryk, 1978; Cook & Reichardt, 1979; Patton, 1978). Interview data from program staff, related services in the region, referral agencies, parents, the management committee, and other stakeholders in LEEP provided the data for the evaluation. Four case studies of children in the program were included to illustrate the program's achievements and the problems faced.

Development of Evaluation Criteria

Since LEEP was considered by both the funding committee and the New South Wales Department of Education to be a pilot early childhood special education program the major evaluation criteria were developed from the funding submission. The program proposed in the funding submission reflected the characteristics which research has identified as being essential components of quality early childhood special education programs (Clunies-Ross, 1981; Heber & Garber, 1975; Karnes, Shwedel, Lewis, Ratts, & Esry, 1981; Kirk, 1965, 1958; Moore, Fredericks, & Baldwin, 1981; Pieterse, 1978; Pieterse & Center, 1984; Schweinhart & Weikart, 1981; Skeels 1942, 1966; Skeels & Dye, 1939). Research-based programs for preschool-aged children have identified a number of characteristics that differentiate between exemplary programs irrespective of their guiding theoretical approach and others that are less than effective (Bronfenbrenner, 1975; Karnes and Zehrbach 1977a, 1977b; Fred and Eleanor Schonell Educational Research Centre, 1982). The Report of the Working Party on early intervention in the northern metropolitan region of Sydney New South Wales accepted similar factors as being critical to effective early childhood special education programs (Early Intervention Guidelines, 1985).

For the LEEP evaluation the criteria identified from the initial submission were:

1. **Referral.** The population to be served should consist of severely handicapped young children. Referral of eligible children should enable the program to meet the special needs of the severely handicapped child through offering home-based, home-based followed by centre-based, and centre-based services.
2. **Assessment.** Interdisciplinary diagnostic assessment should be the basis for determining program eligibility and for developing a joint intervention plan and long term goals for the teacher.
3. **Curriculum.** A curriculum based on normal developmental sequences should enable a systematic and structured set of learning experiences to be designed. The literature on the education of the severely handicapped suggests that curriculum objectives should promote the total development of the child across all developmental areas with an emphasis on age-appropriate functional activities.
4. **Services to parents.** A flexible approach to parent involvement should view the parents as full participants in their child's program and provide support to parents.
5. **Evaluation.** Ongoing internal and external evaluation should enable the monitoring of program quality through the continuous gathering of data, its analysis, and application to improving the program.
6. **Demonstration and dissemination.** The program should be engaged in demonstration and dissemination activities to provide for replication by other programs. In this way, it is possible to share the work that has been carried out with other programs without having to reinvent the wheel.
7. **Staff development.** Staff should have qualifications in early childhood education and in special education. There should also be opportunities for inservice training as an integral part of the program.

There were two important areas were not specifically dealt with in the initial submission. The aspects of program management and coordination of community resources are significant determinants of the effectiveness of a new program. Therefore the evaluation included in the criteria:

1. **Management and administration.** A sound administrative and management structure should provide direction, leadership, communication, and feedback to the staff. Immediate supervisors and higher levels of the administration should support the program.
2. **Coordination of community resources.** All community resources that contribute to the development of a handicapped child should be utilised. There should be good public relations to help community agencies and voluntary groups understand and support the program.

Reporting the Results of the Evaluation

Evaluation findings can be reported in a variety of ways. Informal feedback (either oral or written) of preliminary findings can be useful during the course of the evaluation by providing continuous feedback to assist in decision making about the program. Informal feedback also may avoid the element of sudden surprise in a final report particularly if the findings are not supportive of the expectations of the decision makers.

The evaluative findings were initially discussed informally with program staff to enable them to comment on the results and recommendations. In addition to the informal meetings a series of interim drafts of the report were presented to the Advisory Board. The final report provided an opportunity to present the concrete findings and recommendations using summary presentations of the data to focus on the concerns of the decision makers and other interested parties. The detail of the methodology and the statistical analysis were included as an appendix to the report. After detailed discussion of the final report by the Advisory Board the joint management committee prepared additional comments and provided further data about the program to incorporate in the subsequent funding submission. A summary of the LEEP evaluation findings was subsequently included as one of several case studies of early intervention projects in the report on the state-wide evaluation of the Severely Handicapped Children's Program in New South Wales.

SUMMARY AND CONCLUSIONS

The case for evaluating early intervention programs such as LEEP is clear. The requirement of the funding committee provided a unique opportunity to evaluate a pilot project in its early stage of development. The newness of the program and the lack of prior planning for data collection made the evaluation particularly challenging. The effort was important for a number of reasons.

1. It enabled the program management to meet one of the conditions of funding in order to provide the funding committee with valuable information about the program.
2. It highlighted the program's strengths and weaknesses during its formative phase and provided information on which to base decisions about future policy directions.
3. It provided data about the inevitable difficulties encountered during the initial stages of a program's operation, which should prove useful for the management of other new programs.
4. It emphasised the need to incorporate systematic record keeping and data collection procedures from the start of the program in order to demonstrate child progress and to make possible long term follow up of the children.
5. It illustrated the potential for differing perceptions of appropriate evaluative criteria and the need for evaluators to make their criteria explicit from the outset.
6. It pointed to the danger of interpreting the findings of an evaluation as either an unqualified success or an unqualified failure if a program is still in its early stage of development. The formative nature of such an evaluation precludes more definitive conclusions about program impact. Such a summative judgment really can only be made in the medium term on the basis of data taken over a more extended period of operation.

The experience of the LEEP evaluation provides the basis for two major conclusions concerning the evaluation of early intervention programs. First, funding committees need to mandate some form of program evaluation for all early intervention programs and to commit resources adequate for the purpose. For programs which are wholly oriented towards direct service delivery internal evaluation by program staff is possible if guidelines from the funding committee indicate the nature of the information needs. Wolery and Bailey (1984) recognise the need for program staff to be actively involved in evaluating their own efforts. Goodfellow (1986) has pointed to the usefulness of process evaluation for early intervention programs and has delineated procedures which program staff could adopt. For programs which have research and development as one of their goals, external evaluation is critical because of the policy implications beyond the immediate setting. For this reason dissemination of the evaluation report is important in order to contribute to social policy development and to program replication. In the Australian context it is imperative to use effectively the scarce resources available for early intervention and to learn from the experience of other programs.

Secondly, programs need to plan for evaluation at the outset. This implies the need to maintain an effective record keeping system including child progress data as part of routine procedures. There is always the temptation to regard the time and effort involved as being a waste of valuable teaching time and to neglect the value of the data in contributing to the process of educational decision making and in determining program impact in both the short and long term.

Was the evaluation worthwhile? The evaluation of an Australian program was able to be conducted in a detailed and systematic way with maximum consultation with program management and staff. The evaluation had sought to document the effectiveness of the program in meeting the educational needs of developmentally delayed children. The evaluation did provide data about program management, the particular model of service delivery, and the approach taken to curriculum construction. It considered the way scarce resources were being used in the program and highlighted for the funding committee, program management, and staff issues related to identifying the target population, monitoring child progress, establishing an effective management structure, and coordinating with other service agencies. The evaluation also demonstrated the difficulties of working with a pilot program which had not initially included a planning component while seeking to provide a useful basis for continued program development.

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Chapter 33

A REVIEW OF THE EFFICACY OF EARLY INTERVENTION WITH DOWN SYNDROME CHILDREN

Mark Carter

ABSTRACT

This paper examines research into early intervention with Down syndrome children in relation to threats to internal and external validity, strength of experimental design and statistical hypothesis testing procedures. A total of 42 research studies are reviewed. The evidence obtained does not suggest that claims of efficacy can be accounted for by inadequate experimental designs or a failure to apply statistical testing procedures. Further, a number of soundly constructed, carefully implemented and logically interpreted studies are identified which give preliminary support to the short term efficacy of a variety of general and specific interventions. Long term evidence for the efficacy of intervention is only available in less internally valid research. In the literature reviewed efficacy is claimed for a wide range of complex interventions. Current research does not allow the identification of factors critical to the success of intervention or comparisons of the relative contributions of program components. The external validity of much of the existing research is compromised by a failure to demonstrate representative sampling of subjects, and a bias toward tertiary based or affiliated programs. Increased use of time series and non- equivalent control group quasi-experimental designs is suggested. This strategy should assist in overcoming methodological limitations, aid in identification of efficacious program components and facilitate community replication of research.

INTRODUCTION

Recent years have produced a number of reviews and commentaries relating to the efficacy of early intervention with the developmentally disabled (Combs, 1984; Denhoff, 1981; Dunst & Rheingrover, 1981; Simeonsson, Cooper & Scheiner, 1982). Down syndrome has been considered in some instances within a broader evaluation of early intervention with varied handicapping conditions (Dunst & Rheingrover, 1981; Simeonsson et al., 1982). Reviews of the literature dealing specifically with Down syndrome (Combs, 1984; Hanson, 1979; Mitchell, Parker & Ward, 1981; Pieterse, 1978) provide primarily descriptive analyses and have given limited consideration to factors such as experimental design and threats to validity. This paper examines experimental literature on early intervention with Down syndrome children in relation to threats to internal and external validity, strength of experimental design and the use of statistical testing procedures.

Evaluation of early intervention has been restricted by methodological problems including ethical constraints in the use of true experimental designs (Simeonsson et al., 1982). In reference to early childhood special education, Odom and Fewell (1983) have stated that control groups are not likely to become more accessible in the future. A detailed review of experimental design in early intervention studies with organically handicapped infants has been provided by Dunst and Rheingrover (1981). Few of the studies reviewed used a true experimental design or other format that enabled confident interpretation. Other reviewers (Simeonsson et al., 1982; Odom & Fewell, 1983) have offered similar critical comment on experimental methodology. The critical question for consideration is whether much of the existing research should be discarded or whether there is some logical way of interpreting and using this data. A possible answer to this question can be abstracted from a paper by Parette and Hourcade (1984) which reviewed the effects of therapeutic intervention on motor function in cerebral palsy. Rather than considering studies individually, they examined the pattern of results of research across increasingly rigorous experimental designs and with the use of statistical hypothesis testing procedures. A marked decrease in the evidence for efficacy of intervention with increasingly stringent research designs and, to a lesser degree, a decrease in claims of efficacy with application of statistical procedures were found. Whilst Parette and Hourcade (1984) were cautious in interpreting their findings, the evidence suggested that, to a large extent, efficacious results may be accounted for by inadequate research methodology.

This review applies the basic strategy of Parette and Hourcade (1984) to literature dealing specifically with Down syndrome. The proposition that positive results are not just a product of insufficiently stringent research methodology would be strengthened by two findings. Firstly, the proportion of positive results claimed would not be expected to decline remarkably as strength of experimental design increases. Secondly, the application of statistical hypothesis testing procedures would not be expected to markedly influence claimed results.

METHOD

Selection of Studies

An adaptation of the Simeonsson et al. (1982) definition of early intervention is accepted for the purposes of this review. Early intervention is defined as systematic intervention between birth and five years which is essentially experiential in nature. This includes educational and therapy programs but excludes pharmacological or dietary intervention.

There are a number of obvious reasons for selecting Down syndrome children as subjects for research into early intervention:

(1) They are easily identified (usually at birth) and can be enrolled in programs at an early age.
(2) They represent a large sub-group of the developmentally disabled.
(3) They are relatively homogeneous compared with other diagnostic categories such as cerebral palsy.
(4) There is a reasonable body of evidence documenting progress without systematic intervention.

Studies were included for analysis if they provided discrete data on Down syndrome children, active intervention in a general or specific skill area and quantitative comparative data on at least one measure of developmental child progress. Child progress may not be the only or most appropriate measure of program success but it has been the primary measure of efficacy in early intervention (Dunst & Rheingrover, 1981).

Specifically excluded from the review were efficacy claims not supported by quantitative data. Information dealing with attempts to decrease aberrant behaviour was also excluded. Comparisons of progress between early and late entrants to the programs were also not considered as they frequently required a separate evaluation of the study's design and were not generally intended to be the primary evidence for effectiveness.[1]

A literature search from 1970 to 1985 was conducted through medical and educational data bases. Additional studies were obtained through reference lists of papers dealing with early intervention in Down syndrome. A total of 43 of the research papers obtained were appropriate for review and these generated 42 studies.

Classification of Experimental Validity

The term validity refers to the best available approximation of the truth of propositions, including those about cause (Cook & Campbell, 1979). Cook and Campbell (1979) identify four types of validity:

(1) Statistical conclusion validity refers to conclusions made about co-variation based on statistical evidence.
(2) Internal validity refers to the causal relationship between the intervention and results obtained.
(3) Construct validity refers to the extent that a particular cause or effect operation can be accounted for by a defined construct.
(4) External validity refers to conclusions drawn about generalisability of a causal relationship.

Cook and Campbell (1979) suggest a priority ordering of types of validity for applied research as internal validity, external validity, construct validity of the effect, statistical conclusion validity and construct validity of the cause. They also present a strong argument for the primacy of internal validity for both applied and theoretical research. In this review primary consideration will be given to issues of internal and to a lesser extent external validity.

The following threats to internal validity are defined by Cook and Campbell (1979) and further discussed by Dunst and Rheingrover (1981) in specific relation to early intervention research. Brief definitions and comments on possible sources of invalidity are discussed here — for full discussion of the criteria used for evaluating validity refer to Carter (1986).

(1) History and selection-history interaction.
History is a threat when the observed effect could be due to any historical event other than the treatment. History and selection may interact when observations of different groups are

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[1] Although evidence favoured early program entrants in no case was random assignment used in the allocation of subjects to early and late groups.

not made simultaneously or if groups come from different locations. Local history can influence results in these instances.

(2) Maturation and selection-maturation interaction.
Maturation refers to changes in subjects that are not due to the experimental treatment. Maturation may interact with selection when experimental groups are maturing at different rates. A systematic decrease in maturation rate with increasing age has been well documented in Down syndrome children (Centerwall & Centerwall, 1960; Clements, Bates & Hafer, 1976; Dicks-Mireaux, 1972; Melyn & White, 1973; Morgan, 1979). This makes maturation- selection a very plausible threat when subjects of different ages are compared. Performance differences in studies using historical comparison groups could be a product of a generalised increase in competence of the Down syndrome population (Dunst & Rheingrover 1981). Thus, selection-maturation interaction is a possible threat to research using historical comparison groups.

(3) Testing.
Testing is a threat when the observed changes could possibly have been due to exposure to the testing situation. The use of the target behaviours drawn from the testing instrument creates a threat because programming may familiarise and sensitise subjects to subsequent testing (Dunst & Rheingrover, 1981). For the purposes of this paper, research was considered internally valid for testing if exactly the same items were not used for both testing and teaching (i.e. testing and teaching differed in presentation and/or, materials and/or criteria). This standard is considered less than satisfactory but a more adequate solution is unlikely until the fundamental issues of program content selection and appropriate measures of efficacy are resolved. Further coverage of these issues is offered by by Carta and Greenwood (1985), Garwood (1982), Meisels (1985) and Zigler and Balla (1982). Continual testing of teaching targets is a characteristic of some time series experiments. In these cases testing may not be a threat if performance improvements can be clearly related to introduction of the treatment rather than the ongoing testing.

(4) Instrumentation and selection-instrumentation interaction.
Instrumentation refers to changes in the testing instrument over time. Selection-instrumentation interaction is a possible threat when groups score at a different mean on a scale where intervals are not equal. This is especially a risk when using some criterion referenced instruments.

(5) Regression.
Regression refers to the tendency of extreme scores to drift towards the mean with repeated testing. Selecting subjects on the basis of low scores makes regression a definite threat. Uniform regression is less likely if subject assignment to groups is not random, although, for the purposes of this paper it will only be scored as a threat if marked differences in pre-test scores are apparent. Multiple pre-test measures can be used to evaluate whether regression is a threat to internal validity (Cook & Campbell, 1979).

(6) Selection.
Selection is a threat when differences in an effect could be due to subject selection. It is a threat in all instances where assignment to experimental groups is non-random.

(7) Attrition.
Attrition occurs when there are fewer subjects reported in the analyses than were included in the original experiment. A specific instance of attrition involves reporting of average ages for

acquisition of a particular skill without data on all subjects being presented. It is possible that the children not reported may have attained skills at a much later age than those reported (Dunst & Rheingrover, 1981).

(8) Ambiguity about direction of causal influence.
This is a particular threat in cross-sectional studies where temporal order is unclear. This was not relevant to any of the studies reviewed.

(9) Diffusion or imitation of treatments.
Transfer of information may occur when groups can communicate freely. This was generally an improbable threat in the research under review but it needed to be ruled out when subjects already involved in a program were assigned to different groups for additional treatments (e.g. Harris, 1981a, b).

(10) Compensatory equalisation of treatments.
When an experimental treatment is generally considered desirable an administrative reluctance to tolerate inequality in service delivery develops. This does not appear to be a prominent threat in the type of research under review, however, it may explain reluctance to use true experimental designs.

(11) Compensatory rivalry by respondents receiving less desirable treatments.
In instances where assignment of subjects is made public, control groups may work to offset differences. This does not appear to be a significant threat in research into early intervention.

(12) Resentful demoralisation by subjects receiving less desirable treatments.
Subjects receiving less desirable treatment may become despondent or angry. Resentful demoralisation does not appear to represent a very probable threat to internal validity in the type of research being considered.

Cook and Campbell (1979) list threats to external validity in terms of statistical interaction effects:

(1) Interaction of selection and treatment.
If a sample is obtained because of specific characteristics (e.g. parents seek service), generalisation to subjects without these characteristics can not be assumed. The onus is placed on researchers to state how samples were obtained.

(2) Interaction of setting and treatment.
Results obtained in one setting may not necessarily be replicable in others. Rossi (1978) points out that human services are highly operator-dependent. The 'treatment' and its mode of delivery are functionally inseparable. Intervention procedures that are effective in a tightly controlled research setting may not be robust and will not necessarily be effective when delivered in applied settings (Rossi, 1978). Problems replicating results in the community may be due to limitations in skills or resources, or conversely, could be a result of overly sophisticated treatments that can not be delivered in a reasonable way by typical service delivery organisations. Further, delivery of services in either tertiary or community based settings may add some unintended treatment to the basic intervention — for example, prestige or the availability of on-tap expertise. In the long term, community based services seem the most likely location for provision of the bulk of early intervention to delayed children including those with Down syndrome. Tertiary sponsored experimental programs and model classrooms, particularly those physically located in institutions, need to

demonstrate that their results can be generalised into community settings. For the purposes of this paper, research in institutions will not be accepted as externally valid for this factor unless evidence is given of replication in the community.

(3) Interaction of history and treatment.
Specific short term historical events may effect experimental outcome. This would generally appear an unlikely threat in early intervention research since significant historical events, such as the development of a new drug, are not usually transient — the same conditions would apply in subsequent replications. The case of illness might be an exception here, although it would be expected that any unusual illness would be reported.

Classification of Experimental Designs

The broad classification of experimental design proposed by Cook and Campbell (1979) has been modified for this paper. Experimental design classifications were as follows:

LEVEL 1 Quasi-experiments that usually do not permit strong tests of causal hypothesis.

- (a) Studies using historical comparison groups or single groups with pre-test and/or post-test
- (b) Studies using non-equivalent control groups with post-test only

LEVEL 2 Quasi-experiments that usually do permit strong tests of causal hypothesis.

- (a) Time series designs
- (b) Studies using non-equivalent control groups with pre-test and post-test

LEVEL 3 True experimental designs.

Studies at design level 2 frequently use components of both non-equivalent control groups and time series designs. The three levels of design are characterised by an increasing ability to rule out threats to internal validity. The type of experimental design is not an absolute determinant of interpretability, although it does provide a general guide. In evaluating any research the emphasis should be placed on the researcher to rule out threats to internal validity. Failure to confidently eliminate threats means that subjective judgments are forced about the plausibility of claimed causal effects of treatment.

Program Classifications

Following an initial survey of the literature, five broad categories of program were devised:

(1) Behavioural programs were characterised by the use of operant behavioural technology. Implicit to operant technology is the systematic manipulation of consequences. Use of other techniques including shaping and task analysis were apparent in some studies. The setting of specific objectives and ongoing data collection were identified as components in most behavioural programs. The behavioural approach dictates the training methodology rather than the intervention targets.

(2) The therapy-motor approach showed a strong motor emphasis and used a specific technology usually based on a theoretical model of 'pathological' human development. Harris (1981 a, b) for example, used the 'neurodevelopmental model' pioneered by Bobath. Aims of treatment included the normalisation of muscle tone, and the '. . . facilitation of righting,

equilibrium and protective responses as a foundation of normal patterns of movement' (Harris, 1981b: p.341). Training in non-motor areas is evident in some examples of the therapy-motor approach, although, this generally takes the form of suggestions on play and handling rather than specific training objectives.

(3) Enrichment programs attempted to provide exposure and experience as opposed to teaching specific skills. Presumably children are expected to learn appropriately as a by-product of the exposure alone. A strong training technology is not usually apparent, rather, the child is given what could be termed a 'stimulation bath'.

(4) The 'other' category represents the remaining studies except those that could not be classified on the information available.

(5) The last category was reserved for programs unclassified due to insufficient or unclear information.

The term 'general development' has been used to distinguish programs covering multiple skill areas from those that focus on a single skill or skill area. Further analysis of interventions was not attempted due to insufficient specific information provided in many studies regarding content and procedures. An additional confounding variable was terminology differences in those studies that did provide descriptions of areas programmed for intervention.

RESULTS

A summary of threats to internal and external validity and summary of experimental design is provided in Table 1. Threats that were completely ruled out either by experimental design, or were considered implausible, are marked with a plus sign. In some studies information provided was insufficient to rule out possible threats. The letter 'N' indicates that a threat is not relevant to the particular study in question.

Summaries of subject numbers and study duration are provided in Tables 2 and 3 respectively. The pattern of claimed results and use of statistical analyses, across design levels, is detailed in table 4. Table 5 offers a summary of the mean number of internal validity threats remaining at each design level and table 6 summarises the distribution of types of program.

DISCUSSION

There appears to be only marginal evidence for a systematic decrease in the claims for efficacy of early intervention with Down syndrome across increasingly rigorous experimental designs. Support for the efficacy of intervention was claimed in 96% (n24) of studies at design level 1, 92% (n=11)of studies at level 2 and 80% (n= 4)of studies at level 3. These findings are not consistent with the argument that claims of efficacious results are an artifact of inadequate experimental design. Positive findings were not limited to less rigorous research designs and showed only a slight bias in this direction. Evidence at this point for the efficacy of early intervention with Down syndrome children is nearly uniformly positive for most program classifications. Positive results were claimed in 21 of the 22 behavioural studies, and all of the four enrichment, six therapy- motor and six 'other' studies. Two of the three 'unclassified' studies did not conclude that intervention was effective. Five

TABLE I
SUMMARY OF THREATS TO VALIDITY

SOURCE (Additional references)	INTERNAL VALIDITY											EXTERNAL VALIDITY		
*Threat Number	1 HIS	2 MAT	3 TST	4 INS	5 REG	6 SEL	7 ATT	9 DIF	10 EQU	11 RIV	12 DEM	1 RxSEL	2 RxSET	3 RxHIS
DESIGN LEVEL 1A														
Barna et al. (1979) (Bluma et al., 1976; Revill and Blunden, 1979)	–	–	+	–	+	N	–	N	N	N	N	–	–	+
Clunies-Ross et al. (1979)	–	–	–	–	+	N	+	N	N	N	N	–	–	+
Connolly et al. (1980a) (Connolly and Russell, 1976)	–	–	+	–	+	–	–	N	N	N	N	–	–	+
Connolly and Russell (1976)	–	–	+	–	+	–	–	N	N	N	N	–	–	+
Cunningham et al. (1982) (Cunningham and Sloper, 1980)	–	–	+	–	+	–	–	N	N	N	N	–	+	+
Cunningham and Sloper (1977)	–	–	–	–	+	–	+	N	N	N	N	–	+	+
Drash and Stolberg (undated)	–	–	–	–	+	–	+	N	N	N	N	–	–	+
Drezek (1977)	–	–	–	–	+	N	+	N	N	N	N	–	+	+
Esenther (1984a) (Esenther, 1984b)	–	–	–	–	+	–	–	N	N	N	N	–	+	+
Hanson (1976a)	–	–	+	–	+	–	+	N	N	N	N	–	–	+
Hanson (1979) (Hanson, 1977)	–	–	+	–	+	–	–	N	N	N	N	–	–	+
Hanson and Schwarz (1978) (Hanson, 1977; 1979)	–	–	+	–	+	–	–	N	N	N	N	–	–	+
Hayden and Dmitriev (1975a)	–	–	–	–	+	–	+	N	N	N	N	–	–	+
Mitchell et al. (1981)	–	–	–	–	+	–	+	N	N	N	N	–	–	+
Oelwein et al. (1985)	+	–	–	–	+	N	+	N	N	N	N	–	+	+
Skidmore (1982)	–	–	–	–	+	N	+	N	N	N	N	–	+	+
DESIGN LEVEL 1B														
Brinkworth (1973)	+	–	+	–	+	–	+	+	+	+	+	–	–	+
Brinkworth (1975)	+	–	+	–	+	–	+	+	+	+	+	–	–	+
Canal (1978)	–	–	+	–	+	–	+	+	+	+	+	–	+	+
Connolly et al. (1980b) (Connolly and Russell, 1976)	–	+	+	+	+	–	–	+	+	+	+	–	–	+
Hayden and Dmitriev (1975b)	–	–	–	–	+	–	–	+	+	+	+	–	–	+
Hayden and Haring (1977) (Hayden and Dmitriev, 1975)	+	+	–	–	+	–	+	+	+	+	+	–	–	+
Ludlow and Allen (1979)	–	–	+	–	–	–	–	+	+	+	+	–	+	+
Nulman (1977)	–	–	+	–	+	–	+	+	+	+	+	–	+	+
Pieterse (1978)	+	+	–	–	+	–	–	+	+	+	+	–	–	+
DESIGN LEVEL 2A														
Dickson et al. (undated) (Bellamy et al., 1975)	+	+	+	–	+	N	+	N	N	N	N	–	–	+
Dmitriev (1979)	+	+	+	–	+	N	+	N	N	N	N	–	–	+
Hanson (1976b)	+	–	+	–	+	N	+	N	N	N	N	–	–	+
Jeffree and McConkey (1974)	+	+	+	–	+	N	+	N	N	N	N	–	–	+
MacLean and Baumeister (1982)	–	–	–	–	–	N	+	N	N	N	N	–	–	+
Salzberg and Villani (1983)	+	+	+	–	+	N	+	+	+	+	+	–	–	+
Waters and Siegel (1982)	+	+	+	–	+	N	+	+	+	+	+	–	+	+
DESIGN LEVEL 2B														
Cheseldine and McConkey (1979)	–	+	–	–	–	–	+	+	+	+	+	–	–	+
Le Prevost (1983)	+	–	+	+	+	N	+	N	N	N	N	–	+	+
MacDonald et al. (1974)	+	+	+	–	+	–	–	+	N	+	+	–	–	+
Piper and Pless (1980)	–	+	–	+	+	–	+	+	+	+	+	–	+	+
Romski and Ruder (1984)	+	+	–	–	+	N	+	N	N	N	N	–	–	+
DESIGN LEVEL 3														
Aronson and Fallstrom (1977)	+	+	+	–	+	–	+	+	+	+	+	–	–	+
Bidder et al. (1975)	+	+	–	+	+	–	+	+	+	+	+	–	–	+
Harris (1981a) (Harris, 1981b)	+	+	+	+	+	+	+	+	+	+	+	–	–	+
Kaiser (1977)	+	–	–	–	+	+	–	+	+	+	+	–	–	+
Kantner et al. (1976)	+	–	+	–	+	+	–	+	+	+	+	–	–	+

NOTES: * Numbers correspond to those in text.
Ambiguity of causal direction eliminated from table.

KEY: + Threat eliminated
– Threat not eliminated

TABLE 2
SUMMARY OF SAMPLE SIZE

DESIGN	* TOTAL STUDY NUMBERS <10	11-20	21-50	50+	TOTAL
1A	4	6	4	2	16
1B	–	2	2	5	9
2A	7	–	–	–	7
2B	4	–	1	–	5
3	1	4	–	–	5
TOTAL	16	12	7	7	42

* Excludes subjects in historical comparison groups.

TABLE 3
SUMMARY OF STUDY DURATION

DESIGN	STUDY DURATION (months) <6	7-12	13+	TOTAL
1A	2	3	11	16
1B	–	2	7	9
2A	7	–	–	7
2B	4	–	1	5
3	4	–	1	5
TOTAL	17	5	20	42

TABLE 4
SUMMARY OF CLAIMED RESULTS AND USE OF STATISTICAL ANALYSES

	CLAIMED RESULT		STATISTICAL ANALYSIS	
DESIGN	+	–	YES	NO
1A	16	–	2	14
1B	8	1	6	3
2A	7	–	2	5
2B	4	1	2	3
3	4	1	4	1
TOTAL	39	3	16	26

TABLE 5
MEAN NUMBER OF INTERNAL VALIDITY THREATS REMAINING

DESIGN	MEAN VALIDITY THREATS
1A	4.6
1B	4.0
2A	1.7
2B	2.8
3	2.2

TABLE 6
PROGRAM CLASSIFICATION

	DESIGN LEVEL 1A	1B	2A	2B	3	TOTAL
BEHAVIOURAL	10	3	5	2	2	22
THERAPY-MOTOR	3	2	–	–	1	6
ENRICHMENT	1	3	–	–	1	5
OTHER	1	–	2	2	1	6
UNDETERMINED	1	1	–	1	–	3
TOTAL	16	9	7	5	5	42

of the behavioural studies focused on language, 16 programmed general development and one pre-academic skills. Those studies referred to in the 'other' group included language programs using a cognitive approach, Makaton signing, symbolic play, parental language training and two studies using vestibular stimulation.

An average of 4.6 threats to internal validity remained in the level 1(a) studies. This body of research could not be interpreted with any degree of confidence if considered in isolation. Level 1(b) design studies were slightly more successful in eliminating threats to internal validity. Four of the nine studies had only three threats remaining, however, most of these appeared significant barriers to confident interpretation. Despite this limitation, the studies of Brinkworth (1975), Connolly, Morgan, Russell and Richardson (1980b) and Hayden and Haring (1977) deserve careful consideration due to their large samples and relatively long durations.

A number of the level 2 studies eliminated sufficient threats to internal validity to allow reasonable causal inference. These are the papers of Dickson, Bellamy, Chamberlain and Steinbock (undated), Dmitriev (1979), Hanson (1976b), Jeffree and McConkey (1974), MacDonald, Blott, Gordon, Spiegel and Hartmann (1974), Piper and Pless (1980), Romski and Ruder (1984), Salzberg and Villani (1983) and Waters and Siegel (1982). Each of these studies has three or less internal validity threats remaining and in many instances these were relatively minor or appeared to be possible rather than definite threats. The study of Le Prevost (1983) had only one threat remaining (maturation) but the interpretability of the research hinges on this internal validity factor. Literature (Carr, 1970; Harris, 1981c; LaVeck & LaVeck, 1977) does not support the assumption of equal rates of progress across developmental areas on the instrument used needed to make the results of Le Prevost's research tenable. The studies of Cheseldine and McConkey (1979) and MacLean and Baumeister (1982) suffer multiple design flaws that limit interpretability. The MacLean and Baumeister (1982) paper may have been dealt with unfairly as one of the dependent variables and some of the subjects were not appropriate for consideration in this review.

The true experimental studies (level 3 designs) of Aronson and Fallstrom (1977) and Bidder, Bryant and Gray (1975) appear to eliminate sufficient threats to internal validity to allow strong causal hypothesis to be drawn and seem logically interpreted. In the case of the Kantner, Clark, Allen and Chase (1976) research, the extent of the validity threats, rather than their number, is of critical significance. Interpretation is limited by the small number of subjects, wide differences in age ranges in groups, pre-test score variation between groups, loss of one control subject and difficulties interpreting the clinical significance of results. In defence of this study, it should be noted that results for Down syndrome subjects were artificially isolated from the main sample for the purposes of this review. The research of Kaiser (1977) leaves multiple validity threats remaining and is acknowledged by the author to be 'virtually uninterpretable' on the strength of instrumentation problems alone (Kaiser, 1977: p.62). The study of Harris (1981a, b) is well designed and executed but claims of efficacy should be interpreted with caution. Statistically significant differences were only found on one of the three measures used (individual objectives) and the clinical significance of this difference could not be sensibly interpreted from the data provided.

It appears that at design levels 2 and 3, internally valid and logically interpreted studies are available to support a number of general and specific interventions (see Aronson & Fallstrom, 1977; Bidder et al., 1975; Dickson et al., undated; Dmitriev, 1979; Hanson, 1976b; Jeffree & McConkey, 1974; MacDonald et al., 1974; Piper & Pless, 1980; Romski

& Ruder, 1984; Salzberg & Villani, 1983; and Waters & Siegel, 1982). Of these studies only the research of Piper and Pless (1980), outstanding for its lack of detail about intervention procedures, did not report positive findings. Support is evident for the behavioural approach (10 studies) and to a lesser extent the enrichment approach (one study). The small sample sises in these studies should be noted. Only one study had more than 20 subjects (Piper & Pless, 1980) and two used single subjects — the mean sample sise was 9.7 subjects. Aronson and Fallstrom (1977) were the only researchers to report an investigation of longer than six months duration. However, interpretation of their finding that intervention effects dissipated 12 months post-withdrawal of treatment is restricted — two additional threats to internal validity (history and attrition) were present at the follow-up. The restricted durations of this sub-group of research studies is most probably a reflection of ethical considerations in long term withdrawal of treatment and greater difficulty controlling internal validity threats over extended periods. The small subject numbers and limited durations allow only the most tentative conclusions and highlight the need for replication and, in particular, long term follow-up.

External validity is an estimation of the generalisability of experimental findings. Of the studies reviewed, 14 (33%) were identified as being delivered in the grounds of a university or tertiary institution (in four cases these were also delivered at home), 14 (33%) were delivered at home, seven (17%) appeared to be delivered in the community, one (2%) in a residential institution and six (14%) were unclassified. In eight cases, programs that were delivered at home appeared to also be university affiliated and all of the unclassified programs had tertiary affiliated authors and were possibly linked with the institution. Thus, it would appear likely that around 66 of programs reviewed were directly affiliated with a tertiary institution. Further, 83% (n=35) of studies (including 6 based on dissertations) had at least one author who was identified as being affiliated with a tertiary institution. Community replication of a university affiliated program was only reported by Brinkworth (1975), Cunningham, Aumonier and Sloper (1982) and Oelwein, Fewell and Pruess (1985). In many instances program replication is rendered impractical because of the poor descriptions of the treatment procedures. Setting-treatment interaction represents a major threat to external validity of the unreplicated research.

The external validity threat of selection-treatment interaction can be reduced by ensuring that the sample is representative of the target population. Selection criteria were not clearly specified in most of the studies and only Ludlow and Allen (1979) presented near convincing evidence that their sample was representative of their local community Down syndrome population, which would be a potential target for intervention. Self-selection of subjects to be involved in intervention programs was the most blatant selection-treatment interaction threat to external validity. It is clear that researchers need to more clearly describe their procedures for selecting subjects and engage in more extensive community replication of effective programs.

Each of the 26 studies that did not use statistical testing procedures concluded that intervention was efficacious. Intervention was claimed to be effective in 13 (81%) of the 16 studies that did use statistical procedures. There is a tendency for efficacy claims to decrease with application of statistical tests. However, even with statistical procedures, four of every five studies report successful findings. These results do not lend strong support to the view that claims of efficacy are solely a product of the failure to apply statistical hypothesis testing procedures. In addition it should be noted that some studies, including research utilising single subject designs, characteristically rely on clinical effect rather than statistical significance to evaluate the efficacy of treatment. Those research studies that utilise statistical hypothesis testing procedures have been identified in this paper. The use of such procedures does not suggest that they have been appropriately applied or correctly interpreted. It was not possible within the scope of this paper to further examine statistical procedures. This represents a major limitation of the analysis.

Support has been claimed for the efficacy of a wide range of interventions ranging from behavioural treatments with developmentally derived content to short periods of vestibular stimulation. It is apparent that the term 'early intervention' (at least as defined here) includes a diverse range of interventions which in some cases appear totally dissimilar in their theoretical premises and practical application. Even when a similar theoretical model is adopted, programs may show differences in organisation, content and emphasis (see Clunies-Ross, 1979; Hanson, 1979; Pieterse, 1978).

The question that must be addressed is whether there are common components that determine the effectiveness of early intervention programs. Could a small number of factors such as parental motivation, engaged training time, content selection or program structure be the critical elements underlying program success? In addition, it is possible that different types of programs may be more effective in particular skill areas. In general, the available literature does not lend itself to an analysis of this type. Program description was not well documented in many instances. A detailed curriculum was obtained for some of the 'general development' programs (Barna, Bidder, Gray, Clements & Gardner, 1979; Clunies-Ross, 1979; Cunningham et al., 1982; Hanson, 1979; Hanson & Schwarz, 1978; Pieterse, 1978). Only a few studies (Dickson et al., undated; Dmitriev, 1979; Jeffree & McConkey, 1974; MacDonald et al., 1974; Romski & Ruder, 1984; Salzberg & Villani, 1983; Waters & Siegel, 1982) documented the effects of well defined treatment procedures on specific behaviours using a design that could be interpreted with confidence. Violation of the integrity of treatment is a possible threat to interpretation of much of the available research. Checks on program implementation by parent trainers were only reported by Cheseldine and McConkey (1979) and Salzberg and Villani (1983) and independent checks on the implementation of intervention by professionals were not available in any of the studies. A number of the enrichment studies would have benefited from independent checks of the conditions in both the the experimental and comparison groups to ensure that a difference in treatment actually existed. The failure to apply implementation checks in most studies is disturbing, especially considering Salend's (1984) comments on the importance of ensuring that treatment conditions are implemented as intended, in special education research.

Overall, the available evidence gives tentative support to the efficacy of early intervention with Down syndrome. However, detail is insufficient to allow judgment about the effectiveness of specific components or techniques. Efficacy is claimed for a wide range of programs, but in many cases there is little information on the exact intervention procedure or the relative contribution of various program components to the outcome. The information currently available does not allow determination of the most effective techniques or programs for particular skills or skill areas. Carta and Greenwood (1985: p.91) argue that current evaluation research has focused on child centred outcomes and has treated the interventions as '... unitary variables that were either 'on' or 'off'.' They go on to suggest that 'A new set of controlled efficacy studies must be undertaken to examine the specific programmatic factors responsible for the positive outcomes resulting from early intervention' (Carta & Greenwood, 1985: p.92). Their view is supported by this evaluation of early intervention research in Down syndrome. Research is now required to initially isolate effective techniques and then to determine relative efficacy if more than one treatment is available. Examples of the possible direction for future research are provided by Bidder, Hewitt and Gray (1983) and Waters and Siegel (1982). Bidder et al. (1983) attempted to compare three teaching methods across a variety of developmental skill areas. Counterbalanced treatments were used over a three month period in a parent administered program. Initial findings suggested that more structured techniques, involving written baselines and aims, combined with modelling and practice, were more effective than verbal suggestion (Bidder et al., 1983). There was also slight evidence for an interaction effect between developmental area and teaching technique, although the small sample sise limited analysis (Bidder et al., 1983). Waters and Siegel (1982) presented some tentative evidence to support parental recording of behaviour as a strategy to increase developmental progress in children involved in language intervention. It would be interesting to investigate whether recording techniques were equally successful when applied across different skills, developmental areas or with parents having varying levels of training skill. The Eco-Behavioural approach advocated by Carta and Greenwood (1985) appears to have the potential to provide detailed information about the effective components of early intervention programs and is worthy of further attention.

More extensive application of quasi-experimental designs could assist in overcoming a number of current problems in evaluating early intervention in Down syndrome. Careful execution of such designs allows tight control over threats to internal validity, obviates the need for withdrawal of all treatment for extended periods and facilitates research using small samples. A number of non-equivalent control group and time series quasi-experimental designs reviewed in this paper (Dickson et al., undated; Dmitriev, 1979; Hanson, 1976b; Jeffree & McConkey, 1974; MacDonald et al., 1974; Piper & Pless, 1980; Romski & Ruder, 1984; Salzberg & Villani, 1983; Waters & Siegel, 1982) have proven effective in demonstrating experimental control and have yielded interpretable results. In recommending the use of quasi-experimental designs in early intervention research Dunst and Rheingrover (1981: p.320) state 'The more independent and numerous ways intervention effects can be demonstrated, the less plausible alternative explanations become.' In addition these types of designs appear suited to a more fine-grained analysis of intervention programs and would facilitate the examination of specific intervention technology. Quasi-experimental designs are more likely to be practical in field settings than true experimental designs and should encourage further community based research which could enhance external validity. Only two of the studies reviewed in this paper appeared to have been conducted in Australia. Quasi-experimental designs could assist in overcoming the problems presented by a small and scattered population and could expand our research contribution.

Increased use of quasi-experimental designs could generate a number of problems. Firstly, demonstration of the efficacy of specific techniques with defined behaviours may not necessarily be viewed as constituting acceptable evidence for overall program efficacy. The more extensive and diverse the body of specific evidence becomes, the more difficult this view will be to sustain, although, nothing short of classical research design may be accepted as definitive evidence in some quarters. This is despite informed opinion (Cook & Campbell, 1979; Dunst & Rheingrover, 1981) that quasi-experimental research is a valid and practical alternative in applied settings. The credibility of early intervention can not really be determined based on the child's status in the early years of life (McKay, 1981; Swan, 1981). The current poverty of long term intervention studies with strong internal validity has been previously noted. Quasi-experimental designs assist in solving the ethical problem of withholding treatment by eliminating the need for long term or total withdrawal of intervention. Quasi-experiments that deliberately attempt to minimise the deficit caused by deprivation of treatment are unlikely to add to the long term evidence for efficacy. Research that is inherently less internally valid may need to be considered to answer the long term effectiveness question. Careful examination will need to be made of the extent of remaining internal validity threats in such research.

CONCLUSION

The evidence reviewed in this paper does not give strong support to the contention that efficacy claims for early intervention in Down syndrome are an artifact of insufficiently stringent research design or due to a failure to apply statistical hypothesis testing procedures. Claims of efficacy do not decrease extensively across experimental design levels or with the application of statistical tests. Approximately 93% (n=39) of the 42 research studies claim support for the efficacy of intervention. In addition, well designed and logically interpreted studies are identified that support the short term efficacy of a number of general and specific interventions. The strength of conclusions that can be drawn from this sub-group of studies is limited by small samples, lack of replication, limited study duration and lack of long term follow-up. External validity is compromised, as much of the existing research is university based and/or affiliated and fails to demonstrate representative sampling of subjects. There is a clear and critical need for continuing replication of effective programs. In general, the available research does not allow identification of critical components of intervention or comparisons of relative effectiveness of components. More extensive use of time series and non-equivalent control group designs is suggested to assist in overcoming methodological problems and in examining efficacy of specific components of intervention programs.

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Sue Bettison is currently Director of Professional Services, Autistic Association of N.S.W. Prior to that she was involved in the management and establishment of Developmental Disability Services for the N.S.W. Department of Health, and in the preparation of policy statements for the Richmond Program. She is currently on the Committee for the Commonwealth Severely Handicapped and Children in Residential Institutions Programs and is the N.S.W. Branch President of ASSID.

SANDRA BOCHNER

Sandra Bochner, Senior Lecturer in the School of Education, Macquarie University, is involved in intervention programs for young developmentally delayed children at the Special Education Centre which is located within the University. Her other research interests include issues related to the development of children living in residential care situations, and the educational problems presented by children with severe learning difficulties.

VERITY BOTTROFF

Verity Bottroff, Lecturer in the Bachelor of Education (Special Education) course, South Australian College of Advanced Education (S.A.C. of A.E.), is currently Coordinator of the Diploma of Applied Science (Developmental Disabilities) course at S.A.C. of A.E. Verity is also involved in researching the area of Freestyle Martial Arts as a community recreation program, providing opportunities for children, adolescents and adults with disabilities to gain competence skills which can assist their integration into the local community.

MARGARET BULL, JOY GIBSON AND ANDREW MORRISH

Margaret Bull leads the multi-disciplinary team which provides home and community based services for babies and young children with visual impairment and on-site services to preschoolers to 6 years of age, who are multiply impaired. Margaret believes that early intervention services to these children and their families should be developmentally based and provided by specialist staff receiving constant in-service training. Evaluation of services and a flexible response to expressed needs are paramount in the effectiveness of these services.

Joy Gibson (TPTC, TTCD, B.ED.) Co-ordinates Curriculum Development in the Preschool and Multi-handicapped Unit of the R.V.I.B. Educational Centre for Blind Children. Joy has vast experience in Special Education and has worked with Hearing Impaired and Visually Impaired children in Victoria and the Northern Territory. Joy is strongly committed to bridging the 'gap' between Curriculum Development and Teaching Practice.

Andrew Morrish (Dip.Tch (Primary), Grad. Dip. Ed. Studies, Grad. Dip. Movement and Dance, Grad. Dip. Arts Ed.) is the Preschool Resources Officer and Preschool Movement and Dance specialist. Andrew is interested in the Curriculum process especially in relation to Expressive Areas, and is involved in the development of Dance Therapy in Victoria.

JULIE CAMPBELL

Julie Campbell was born and educated in New Zealand and taught in country and city schools there before travelling to Oxford and working on Piagetian research. A move to Sydney in the sixties and three small children gave impetus to the establishment of a playgroup which subsequently became the foundation for playgroups in N.S.W. After further University studies she became a lecturer in Child Development at S.K.T.C., now I.E.C.S. Postgraduate work at Macquarie intensified her interest in young children with special needs. Her current research on play and language in young blind children has a number of implications for early intervention.

MARK CARTER

Mark Carter graduated as an occupational therapist from Cumberland College of Health Sciences in 1980 and is currently completing a Master of Arts in Special Education at Macquarie University. Mark has worked in the area of early intervention for six years. Areas of interest include early intervention and instructional technology.

GRAHAM CLUNIES-ROSS

Graham Clunies-Ross established the EPIC Centre while he was Head of the Psychology Department at Preston Institute of Technology (now Phillip Institute of Technology) from 1974-78. Since 1979 he has been Head of the Educational Psychology Department at Melbourne College of Advanced Education. In addition to early educational intervention, his current major professional interests are in the field of integration, working with teachers, parents, and students in order to assist regular schools to educate successfully children with disabilities.

ERROL COCKS

Errol Cocks, B.A., M.Psych., M.A.Ps.S., is a Senior Lecturer, Department of Community and Behavioural Studies, W.A. College of Advanced Education. He is involved in teaching in the areas of habilitation studies and human service administration and program development consultancy in the areas of disability and aged services. Errol is a member of the Council of People with Disabilities (W.A.) Inc., and a consultant in disability services to the Commonwealth Department of Community Services and Health.

JUDY CROLL

Judy Croll is early childhood trained and has had a long association with the field of early childhood education. She has had experience as a preschool teacher, initially with non-disabled children but subsequently with special needs groups. In association with Joy Goodfellow, she submitted the initial proposal for funding that led to the establishment of the Early Learning Service. Most recently, she has lectured at the Institute of Early Childhood Studies in Sydney. Judy gained a B.A.(Hons) degree at Macquarie University and is currently completing requirements for a Masters degree. Judy has been president of the N.S.W. Early Intervention Association for the past two years.

PHIL FOREMAN

Phil Foreman is Director of the Special Education Centre at the Hunter Institute of Higher Education (formerly Newcastle C.A.E.). A former teacher and school counsellor, his research interests are in the fields of early intervention and developmental disabilities. He participated in the establishment of early intervention programs in the Newcastle, Gosford, Maitland, Muswellbrook and Port Macquarie areas and has encouraged the use of Newcastle Special Education Centre as a regional in-service centre for staff working in early intervention. He has a particular interest in treatment approaches in Down Syndrome, the topic of his doctoral thesis, and has published several papers in this field.

ANNETINE FARRELL AND MARY GLUE

Annetine Farrell originally trained as a nurse and *Mary Glue* as an occupational therapist and together they founded the Noahs Ark Toy Library in 1971 after reading about one overseas. Now as co-directors of the Toy Library they have helped its services to develop in many directions. Both are interested in children's development and family interaction and see play as a natural way to intervene with children, as well as a good medium to get through to parents and children. As Mary says, 'Toys are your means of communication'.

JOY GOODFELLOW

Joy Goodfellow is a Senior Lecturer at the Institute of Early Childhood Studies, Sydney College of Advanced Education. She teaches early childhood special education in both the undergraduate and graduate program with her particular interests being program development, evaluation and policy making. Her publications include a series on Early Education of Young Children with Special Needs. Joy was involved in the establishment of the Education Support Service at Chatswood, the first itinerant support service of its kind to be established in New South Wales. She is a committee member of the NSW Early Intervention Association.

ALAN HAYES

Alan Hayes is a senior lecturer on the staff of the Fred and Eleanor Schonell Special Education Research Centre, University of Queensland. After a primary school teaching career in N.S.W., and postgraduate studies in the School of Behavioural Sciences, Macquarie University, he joined the staff of the Schonell Centre in 1978. For several years he was actively involved in projects monitoring the implementation of early intervention programs, nationally and in Queensland. Currently, his major research interests include studies of the social and cognitive development of children with Down syndrome, focusing particularly on the developmental significance of their family relationships.

MURIEL HEALEY

Muriel Healey has training and experience in the disciplines of education and social work. She was the Program Advisor for the Home Base Preschool Program in the Mount Druitt Early Childhood Project which was supported by a grant from the Bernard Van Leer Foundation which was administered by the School of Education at Macquarie University, N.S.W.

ALISON JACOB

Alison Jacob is the Southern Regional Special Education Officer for the Education Department of Tasmania. She is responsible for the day-to-day functioning of Special Education within the region. She has a particular interest in education of severely handicapped students and early intervention.

BARBARA E. KENNETT

Barbara E. Kennett has held several positions with the Autistic Association of New South Wales, including the position of Assistant Director of Professional Services. She has qualifications as a teacher of severely and profoundly handicapped children, holds a Bachelor Arts degree (with honours in psychology) from St. Francis Xavier University, Sydney, Nova Scotia, a Master of Arts degree from Ohio State University, and is a member of both the Australian Psychological Society and the Institute of Private Clinical Psychologists of Australia.

CORAL KEMP

Coral Kemp has had experience in teaching both regular and special education classes. From 1975-6 she undertook a Masters Degree in Special Education at Macquarie University. It was during this period that Coral developed a major interest in disabled preschoolers. In 1980 she became the first special educator on the S.C.W.A. (Challenge Foundation of N.S.W.) home-based early intervention team. From 1983-5 she was the state-wide Special Education Consultant with the N.S.W. Department of Education. Since that time, Coral has been the executive teacher, student support, at Sadlier Public School, N.S.W. As well as supervising the unit Coral has been responsible for teaching the special language class (4-8 year olds).

KATHERINE KENNY

Katherine Kenny is the Senior Special Educator with the Children's Services Office in South Australia. Her formative professional years were mainly spent with the N.S.W. Education Department teaching and learning in priorities and special education areas in outer south western Sydney and Newcastle. After teaching in a number of primary schools and special classes, she became the inaugural director of the Hunter Valley integrated Special Education Preschool. Since arriving in South Australia Katherine has held a number of positions prior to her present position. She participates in the activities of the Australian Association of Special Educators (National Early Childhood Interest Group Chairperson 1987 Conference) and has been the Chairperson of the Early Intervention Association of S.A. (Inc) since March 1987.

DAVID LEACH, HAL SWERISSEN AND PAULINE LEACH

David Leach is a senior lecturer in psychology at Murdoch University, Perth, Western Australia. He has published and lectured widely in the area of applied educational psychology in Australia, U.K. and U.S.A. and is co- author of *Learning and Behaviour Difficulties in School* (Open Books, 1977) with E.C. Raybould. He worked for eight years as an educational psychologist with education authorities and taught at Birmingham University in the U.K. before moving to Australia. David's main teaching commitments are on the Masters in Applied Psychology course at Murdoch. He is currently developing and evaluating cost-effective intervention programs for use by teachers and parents with pre-school and school-age children who experience mild to severe difficulties with basic academic skills. He is also interested in service delivery issues in psychology and special education. In addition to teaching and research, David has contributed to the development of professional psychology through his work as Chairperson of the Australian Psychological Society's Board of Educational and Developmental Psychologists, Secretary of the Division of Professional Affairs, and member of the Psychologists Board of Western Australia. He was elected Fellow of the British Psychological Society in 1987.

Hjalmar Swerissen is currently a lecturer in psychology and coordinator of the Graduate Diploma in Community Health in the Department of Behavioural Health Sciences, La Trobe University in Melbourne, Victoria. While a tutor at Murdoch University, Hal worked primarily in the area of applied educational psychology and took a special interest in handicapped children. Since his appointment at La Trobe, he has concentrated more on the application of psychology to health and rehabilitation issues. He edited *New Developments in Worker Rehabilitation: The Workcare Model in Australia* (with A. Remenyi and S. Thomas) in 1987 (Published by World Rehabilitation Fund).

Pauline Leach is a special needs co-ordinator at John XXIII College in Perth, Western Australia. She is primarily responsible for the assessment of children with mild to moderate learning difficulties and for their programming and integration within the regular school. Prior to her current appointment, she worked as a teacher in schools for the intellectually and multiply handicapped and was program coordinator for the Autistic Association of Western Australia. Pauline has been a member of numerous advisory committees in the area of special education and is presently a committee member of the Direct Instruction Association (W.A.).

JUDITH LEESON AND JUDY OPOLSKI

Judith Leeson is Director of an early intervention program for families of young children with Down syndrome. The Developmental Learning Program is sited within the South Australian College of Advanced Education, and is co-sponsored by the Down Syndrome Association of South Australia and the School of Special Education. She has worked with young children with autism, and Down syndrome, and has a particular interest in working in partnership with families.

Judy Opolski became involved in early intervention following the birth of her son who has Down syndrome. Through her involvement with professionals she has realised the value of working in genuine partnership to benefit both child and family. She has been active in exploring the roles and responsibilities of parents and professionals.

GEORGE LEWIS AND CECILE FERGUSON

George Lewis who has Ph.D. in early childhood special education from the University of Illinois, has been involved in early childhood teacher education in special education since 1974. He is currently a senior lecturer at Sydney CAE, Institute of Early Childhood Studies with particular research interests in curriculum development and evaluation. *Cecile Ferguson* has a B.Ec (Hons) from Sydney University and is currently completing her Ph.D. in program evaluation within special education. She is presently employed as a Research Fellow within the School of Education at Macquarie University and her research interests include evaluation, early intervention and integration.

ELSIE MAY

Elsie May, a graduate in medicine of the University of Sydney and Fellow of the Faculty of Community Medicine (U.K.) has wide experience in paediatrics in England and New South Wales. She has been a Lecturer and Senior Lecturer in Developmental Paediatrics at the University of Birmingham, England, and Lecturer at the University of Sydney. Dr. May is the author of a textbook on Community Paediatrics and author and co-author of various articles and textbooks relating to child development and handicap. At the time of writing, Dr. May was Medical Director of clinical services at the Spastic Centre of N.S.W. and is now in private practice.

TIM MOORE

Tim Moore has worked as an educational psychologist in both Australia and England for eighteen years and completed his doctorate at the University of Surrey in 1981. He now works for the Ministry of Education in student services and was based for three years at Monnington Centre (which provided early intervention programs for hearing impaired and developmentally delayed children). He is current President of the Early Intervention Association of Victoria.

CARL L. PARSONS, IAN SMITH AND STEVEN N. BOWMAN

Carl L. Parsons, is currently a Principal Lecturer in the new Lincoln School of Health Sciences at La Trobe University. Dr. Parsons has a Bachelor of Science degree in Speech Pathology, a Master of Science in Education and a Ph.D. in Communication Disorders and Psychology. Dr. Parsons' interests have been in the area of alternative forms of service delivery. One aspect of this work has been the development of communication camps as described in the book. In addition, Dr. Parsons initiated and coordinated the first weeklong 'Communication Intervention Camp' in 1987. This camp aimed to provide services to the communicatively impaired. Dr. Parsons currently is involved in the use of telecommunication systems to provide services to families. These systems and projects include the use of computers, videos, two-way telephone systems, videodisks, and the AUSSAT satellite to provide services to families in isolated areas of Australia.

Ian Smith was a student in the School of Communication Disorders. He recently completed his Bachelor of Applied Science (Speech Pathology) and plans to work in a country area of Australia and to continue to facilitate the idea of communication camps.

Steven Bowman is currently the Assistant Director, Professional Development, for the Australian Society of Accountants. Mr. Bowman holds a Bachelor of Applied Science (Speech Pathology), a Graduate Diploma in Communication Disorders, a Master of Arts in Speech Pathology and a Master of Association Management degree. He continues to provide consultative services on camp management and the telecommunication options for alternative service delivery to families in isolated areas of Australia. Steven's current duties with the Australian Society of Accountants include financial and marketing responsibility for national professional development including satellite conferencing, seminars, video titles, computer-based training and presentation skills training for presenters.

CHRIS PRATT AND ROBERT GRIEVE

Chris Pratt completed a Master of Arts at St. Andrew's University and a Doctor of Philosophy at the University of Oxford. He is currently Senior Lecturer in Psychology and Director of the Child Study Centre at the University of Western Australia. His research interests are in the area of early childhood where he has focused on cognitive, linguistic and social development and the implications of this research for education in the preschool and early school years.

Robert Grieve was Director of the Child Study Centre at the University of Western Australia from 1982-84, before becoming Head of the Department of Psychology at the same University from 1985-86. In 1987 he took up the Chair of Psychology and Headship of the Department of Psychology at the University of Edinburgh. His continuing interests are in aspects of children's intellectual development, their development of communication, and their learning and education in the preschool and early school years.

MOIRA PIETERSE

Moira Pieterse is a Lecturer in Special Education at Macquarie University and has been involved in early education for children with Down Syndrome since 1974, when she helped to found both the Down Syndrome Program at Macquarie and subsequently the Early Education Clinics for delayed or disabled children at North Sydney and Parramatta. Aware of the need for curriculum material for early education, especially suitable for Australian children, she developed the Macquarie Program for developmentally delayed children in conjunction with her co-workers Sue Cairns and Robin Treloar.

PENNY PRICE

Penny Price, is a Lecturer in Special Education at Macquarie University. Her particular interests are the education of young handicapped children, and the acquisition of language and communication skills in children who are developmentally delayed. Her current research is looking at the interactions between mother and child with the purpose of identifying those features which are facilitating, and incorporating this information into current intervention programming.

JUNE ROUSE

June Rouse is employed by the Northern Territory Department of Education in the position of Education Officer Early Intervention. She is based in one of the central education office buildings in Darwin, Tamar House in Mitchell Street. June began her work as a special educationist in the United Kingdom in 1967, having previously been employed as an infant and primary school teacher. Since arriving in Australia in 1974, she has served the Education Department of Tasmania, first as a special school teacher and later as a special education consultant for the state. She was appointed to the Northern Territory Teaching Service in 1979 as a special education adviser and, prior to her current appointment, was the Education Officer Special Education for Darwin North Region. A member of the Australian Association of Special Education, an organisation which she helped to found in Melbourne in 1976, June was for a period of five years (1979-85), a member of the management committee of the Harry Giese Centre (N.T. Spastics Association). She relinquished this position when, as E.O.E.I., she became the Department's programs co-ordinating officer at the Centre.

CATHERINE RUMSEY

Catherine Rumsey, B.A.(Hons I), Ph.D., is Head of the Department of Counselling and Disability Studies at Nepean College of Advanced Education. She holds a N.S.W. Teacher's Certificate and is a trained teacher of hearing impaired students. At the Universities of Sydney, N.S.W. and Pittsburgh, U.S.A. she majored in Education and Psychology with particular emphasis on education of hearing impaired students. She has taught both hearing and deaf children in schools and, together with their parents, in early intervention programs. Dr. Rumsey currently lectures in a number of areas in Special Education including early intervention. Her research publications include journal articles on mothers' perceptions of their young deaf children, the education of hearing impaired students in integrated settings and directories of services for hearing impaired people.

BRONWYN THORNCRAFT

Bronwyn Thorncraft studied for her Bachelor of Arts at Sydney University. She completed her Diploma in Education, specialising in Special Education in 1976. From 1977-1981, she was a secondary teacher of mildly intellectually handicapped students and in 1982, completed a Post-Graduate Diploma in Deaf Education. Bronwyn has been a teacher of the deaf at North Rocks where she gained placement on The Secondary Special List. In 1987, she completed her Master of Arts (Special Education) at Macquarie University.

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